The Third Epidemic:
Finding our Voice in the Culture of
Silence that Surrounds HIV and AIDS

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For Charlene

For what she did, to what she dreamed.

And For Luis

(Wherever you are)

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Abstract

The third epidemic: that of the social repercussions and the fear of AIDS, continues to generate the myths, prejudice and stigma, so inaccurately associated with HIV and AIDS, often silencing those trying to live so positively with the virus and syndrome.

This paper looks to the development of HIV/AIDS education praxis, from London, New York and Aotearoa/New Zealand perspectives; emphasising the need for all of us to question the culture of silence that surrounds the epidemic[s], while acknowledging the fact that we are all affected by the present pandemic, whether we are living with the virus, educating as to the realities of the virus, or simply choosing to believe that it does not exist. It is in developing our own critical-reflection praxis, (whether we be parents, students or teachers), that we will begin to develop more appropriate and culturally sensitive HIV health education praxis within our schools; along with the voice and infused ability to lobby for policy development that will determine its long-term effectiveness.

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Ta siul ag an leanbh - Is fada an siul e.
Creidim i gconai sna mioruilti.

Preface

The Journey to Stand Up

‘What’s the number of dead friends, at which you can stop just sitting quietly, like the good little boys and girls we were all brought up to be...One? Ten? One hundred?’ (1)

I remember David.¹ David worked in an academic department of a university in Aotearoa/New Zealand. Then one day, in the mid 1980s, David tested HIV positive. I did not know David personally, but often saw him on a daily basis, in relation to my own work interests. In time, David decided to leave his job. And someone I knew closely worked instead, in his position.

I remember the atmosphere at the time. A certain silence: the hushed, pervading kind, that might as easily be one continuous sound. There were a few voices. I remember one or two more, trying to dispel (in quiet overtones), the myths that might, or might not, surround the so-called ‘diagnosis’ of HIV or AIDS. But the conversations were almost always conducted in barely audible whispers.

“No. You can’t get it from the coffee mugs,” one reassured another. (I was later informed, she scrubbed all of hers.) And you couldn’t get it from hugging, or from toilet seats. You could, however, get it from semen, blood, syringes and from ‘travelling overseas’. David had, ‘unfortunately’, travelled overseas.

To stand at the very edges of these and other conversations was often, for me, an experience of being on the ‘outside, looking in’. Those who did speak, seemed to be very fluent in discussing the latest media ‘hype’ on AIDS. Unfortunately, the shameful misinformation and misrepresentation of the virus and syndrome (fed to us via the national and international press), served only to fan-into-a-flame, newer and more damaging myths in relation to the AIDS epidemic. If the media insisted on misreporting HIV as AIDS, for example, how were those who so arrogantly regarded themselves as ‘safe populations’ ever going to come to terms with the basic, and correct definitions of the virus, syndrome and related conditions; let alone challenge their own preconceived notions and prejudices in relation to the epidemic?

With regard to David, therefore, hushed silences might be mistakenly considered a ‘mark of respect’; when, in fact,

¹ David is used here as a pseudonym.

they could just as probably be born of the lack of knowledge. And, sadly, it was silently assumed that David's diagnosis was synonymous with the death sentence.

I often wondered how David coped with the silence and the kinder 'sympathies' the 'enlightened' must have bestowed upon him. I continued to see him about the university periodically, fighting more valiantly than I, the notorious Wellington winds. But, in time, I seemed somehow to lose sight of him altogether; to my manic workload, the chronic illness of my sister, the terminal illness of my father. And my own divorce.

To cope with the dramatic changes in my own life, I began to spend more and more time in the bush and mountains of Aotearoa; and less and less time anywhere near the university.

I had graduated as a teacher in 1983, and had left after two years work experience, to complete my Bachelor of Arts and Music degrees. I had also developed specific interests in drama, special needs education and policy development. The months in the mountains were important ones, providing me with the focus I needed to complete a larger work I had been commissioned to write for the Public Advisory Committee on Disarmament and Arms Control, as to the progress and development of peace education in Aotearoa/New Zealand schools.

I completed this work, but in May 1991, was involved in a serious tramping (hiking) incident which left me with something my rescuers called 'pneumonia' but which was to leave me virtually paralysed for the next 4-5 months with muscle coordination so affected that I was unable to work for the next 2 years.

This was a terrible, but oddly significant time in which, as I slowly recovered, I was able to focus much more of my attention on the one thing I wanted to do, more than anything else in life: to somehow use my small experience to write. During this time, I was surprised to find myself accepted into Bill Manhire's creative writing course and, the following year (being unable to work), I began my Master's in Education degree.

By April 1992, I had completed the four required in-course papers of the degree, but did not feel physically strong enough to begin the thesis. It was about this time, that my supervisor suggested that I have a short break away in the European summer, to gain the strength and perspective we both knew I needed to complete the work.

I can remember feeling a little confused by the idea. After all, I hadn't even been able to pay my university fees. I thanked her, took the booklet which offered free food and accomodation, in return for assistance on international community projects and went back to my two-hour cleaning job.

It was later that day, that I rediscovered the booklet, and sat down with a hot drink, to skim through it.

Joanna, my supervisor, had told me of one such scheme, requiring volunteers, for three weeks, in Harlem, New York. The project involved helping to renovate a house for people living with HIV and AIDS.

I thought of David. And the recent sighting of him bundled in a wheelchair. (At first, I had not recognised him, for his being so emaciated.) But then I recognised that same gentle and tolerant gaze; unchanged by the peculiar activities and reactions, of the people around him. I had walked into this foyer, unexpectedly, and I remember moving back from the passages of people. Everywhere about me, even through the window to the street below, people moved (it seemed) in strangely frenetic and unconnected circles. How many months had it been since I had seen David? Or, was it years? Where the hell had I been? And where was I now?

I turned the pages of the international booklet. There were two programmes that caught my attention, in a way that has never happened to me since. The page fell open and I somehow knew I would be travelling, in a matter of weeks. I had become disillusioned with academic spirals. I had very little in terms of savings, but I looked about my room. And knew that I could sell my piano and two guitars, to start with.

The next morning I called the United States. The first scheme was not an HIV/AIDS related project. But, for personal reasons, it was the first I needed to be on. I knew my chances of being accepted onto either scheme were slim. For a start, only about 16 people were required for either programme. And I knew I had already missed the deadline for written application.

For some reason, however, I was accepted onto the programmes which left me exhilarated, but extremely incapable of explaining to anyone how I was going to get to the United States and survive financially for 6-8 weeks.

There were also the concerned comments: 'But you've never been out of New Zealand...You spend all your time in the mountains. And now you're going to New York?'

People, however, were supportive. They watched me as I sold my piano and guitars. They helped me as I prepared to dump half the contents of my flat at a garage sale. And, 6-7 weeks later, I left.

'See you, in three or four weeks,' some of their looks could have said. And seriously, I wondered with the money I had, if I would be able to last even that long.

I will not describe the details of the next few weeks, except to say that the aim was to give, but I gained more than I ever could repay to the Abenaki Indian peoples of the Mississquoi.

Later, I was to lose most of my belongings, heading down to Miami, (not realising that a hurricane was in progress). And I lost the rest of anything I owned in downtown Manhattan.

It was late summer, approaching autumn, when I finally arrived in New York. And I quickly developed a love/hate relationship with it. I had never seen the very rich and the very poor, literally living and dying in such close proximity. I remember thinking or reading somewhere about the difference between the cities of Washington and New York. And could only agree that, if Washington were a monument to war; then New York City could only be a monument to capitalism.

I had certainly *expected* the homeless. But not in the numbers of severely malnourished human beings, who were so obviously trying to survive under sheets of paper, rubbish and bits of cardboard (if they were lucky enough to find the cardboard); while wealthy, furred coats carefully wove the course of their stringed-poodles, about them.

I had never seen so many limousines. And so many people begging to the point of collapsing, on the subway tracks. Nor had I seen the violence. Or the numbers of people, left begging with their cardboard and paper placards: 'Please help me. I have AIDS'.

There were times when I really hated New York. At times I felt it could only be compared to a third world society; with its towered conglomerate of people, so flagrantly boasting its first world status.

But it was at 145W, 130th Street, that my life was dramatically changed. It was here, that I came to live and work, for a short time, with the newly developing community, *Stand Up Harlem*.

My own personal journey to Stand Up is further described in co-current work, as this community of people has been the inspiration and the focus of my own life-changes, over the last three years. For now, I will merely begin to introduce some of its empowering pedagogy and action-reflection praxis as part of this thesis; as I believe that it is a powerful example of peoples finding their voice and developing their own HIV/AIDS education praxis, against the tremendous odds of poverty, fear and prejudice, so characteristic of the present epidemic.

The initial piece of work is written to the courage and determination of those who founded Stand Up Harlem. And all those who work so closely in the community on a daily basis; especially for Louis Jones, Willie, Phyleccia and Paula Palmateer.

It is written for David, the New Zealander who returned to his own country in 1986 and had the ability to educate without words. It is written for the gentle hope of Byron and many other New Zealanders who came to London, in an effort to live more positively with the virus and the syndrome.

It is written for Charlene who, at 23, has lived positively with the virus for nine years. It is for her mother, who died within one week of being diagnosed with AIDS. And for her two lovers, whom she watched die. This is also for her three children, two of whom are sero-positive. And for Richard, on the doorstep of 145W, 130th street.

It is written for Phylis and her life-strength; Joseph who, at the age of 27, had lost almost his entire family to AIDS. And for Lucy, in search of her mother and her own loving reflection.

This is for Chestna who wanted to speak, but chose to sing; Beverley, at the backyard fence, Hanif with his wicked

sense of humour. And Howard with his enthusiasm to teach about living positively with the virus.

I write for all those who saw through my colour, to the recovery of my own life; especially for Josephine, the healer in the white dress, who cured me of recurring illnesses, encouraged me to write the story and pointed out the path.

I write this for Mary; her silent, but watching face at the dinner table. And to the memory of her 24 years, ended so violently the next day.

I write this especially for the loss of Luis.²

I write this to the memory of our memories. May we never be silenced or blinded to things we've seen and heard.

'Remember that some day the HIV/AIDS crisis will be over. And when that day has come and gone, there will be people alive on this earth. Gay people and straight people. Black people and white people. Men and women will hear the story, that once there was a terrible disease. And that a brave group of people stood up and fought. And in some cases, died so that others might live and be free.

I'm proud to be out here today, with the people I love. And see the faces of the [people] who are fighting this [epidemic]. And be a part of that fight.'²

1. Kramer L. *Reports from the Holocaust*. New York: St Martin's Press, p165.

2. Kramer L. Op cit, p277

² This does not refer to Louis Jones, who is still cofounder of Stand Up Harlem.

Introduction

In August 1992, I came to work at the community of Stand Up Harlem, New York. Although I was initially working with a group of international volunteers on the physical renovations of the original community house, we were all invited to become part of the daily activities, meals and meetings of community life.

It was here that I began to experience the action-reflection praxis and process of conscientisation, that was to change my life. I spent two summers at Stand Up Harlem; coming back to England when my visa expired and teaching on the East End of London to finance travel and the writing I had been encouraged to continue, while there.

This thesis includes only some of the voices of those interviewed both in London and New York, over the past two years. It is, in itself, one small part of a much larger process, to be continued over the next three years.

The aims of this thesis are three-fold and are as follows:

1. To give voice to some of those living so positively with HIV/AIDS in New York and London, as they create their own communities of meaning and resistance to the myths, prejudice and stigma, so often and inaccurately associated with the virus and syndrome.

It is my intention to present some of the powerful HIV/AIDS education praxis developing in New York and London in order:

- (a) To begin a renewed process of identification and empowerment among those still living in the isolation of the culture of silence that so often surrounds their 'diagnosis' of HIV and AIDS
 - (b) To educate, as to the realities of such a 'diagnosis' (ie silence = death, but HIV does not)
 - (c) To further encourage those working in the field of HIV/AIDS education, to continue to develop their own community networks of meaning and resistance, and to ensure that there is school policy and government legislation to protect the long-term effectiveness of their health education programmes.
2. To present some of the research already conducted in a New Zealand context as to the successful development of HIV/AIDS education praxis; alongside the findings that there is much parent, teacher and student support for the

continued development of such praxis and policy formation, nationally and within the schools of Aotearoa/New Zealand.

Together with this second primary aim, I would like to investigate the nature of the HIV/AIDS 'epidemic', as defined by Dr Jonathan Mann of the World Health Organisation Global Programme on AIDS, as it pertains in effect, to three global epidemics.

The first epidemic being the 'silent', 'unrecognised' development of AIDS through the 1950s to 1981. The second epidemic is the one we are presently witnessing and have been experiencing since the 1980s, in its more visible form. The third is identified as the social epidemic: the social repercussions and fear of AIDS that, in my opinion, not only tend to keep those living with the virus and syndrome silenced and isolated from/by society; but prevents the important links being established between our developing health education programmes and the development of effective policy and government legislation that should provide us with the financial assistance and resources to maintain them.

3. To investigate the ideologies of Freire (1972) and Boal (1979), as a means by which we can all find our voice, enter into dialogue, network and begin to form our own HIV/AIDS education praxis and policy; encouraging the process of our own conscientisation, as well as that our students, in a peer-centred/community-oriented and culturally sensitive context.

Methodology

In conducting the research for this thesis, I have used Grounded Theory Methodology, as espoused by (Glaser and Strauss). The emphasis has been on the use of qualitative data, in order to generate theory that might provide clear categories and hypotheses that current ones might, in turn, be verified in present and future research.

It is my opinion that we, as a society, have been overwhelmed over the past decade, with the empirical data and generalisations of quantitative studies in relation to HIV and AIDS; which often serves to alienate (still further), those living with the virus and syndrome, while encouraging still larger populations of society to withdraw into a

pessimistic, apathetic (if not prejudiced), view of the epidemics.

This is particularly so, when considering the distortion and generation of such 'facts' by our respective governments and the media tycoons who, although consistently presented with the correct definitions, facts and realities pertaining to the epidemic(s), insist on keeping us in a perpetual state of prejudice and ignorance, as to their reality.

In writing this thesis, I would like to present (as already cited in the original aims of this work), some of the data generated from the voiced realities of those presently living with HIV and AIDS in the cities of London and New York, 1992-1994.

Although I had designed a series of questions to be asked of each interviewee, these were not listed in any particular order or in a written form at the interviews; but acted merely as prompts to be used (if necessary), at certain stages of the interviews. This was so that the interviewee could have 'free reign' to generate her/his own reality in the course of their dialogue and for whatever time s/he felt most comfortable. The interviews would last anything from 20-90 minutes; with the average interview time being that of 45 minutes.

My role as interviewer was simply that of facilitator. I was to speak as little as possible, during the course of the dialogue; only asking one of the original series of questions, if it were not covered in the course of the interview. (The latter was not often required, except when asking the interviewee if they had any message to record for those living with the virus in New Zealand;³ and for those elsewhere, who might never have considered their own part in affecting or being affected by the repercussions of the third epidemic.)

This initial process meant listening carefully to every aspect of the dialogue in process; being aware of environmental surroundings and interruptions;⁴ while including those who might walk in on the interview process, and want to be part of it, at the interviewee's invitation.

All of the interviewees had come to know me over a period of days or weeks; had chosen to be interviewed; as well as the time and place of interview. Each was fully aware that the dictaphone used, could be switched off at any stage

³ Some of these messages are included in the appendices.

⁴ It is not always easy to find space in a crowded community: some of the interviewees chose to sit out the front on the stoop, feeling more comfortable amidst the street noise and activities; while others tried to find a corner in the tiny backyard allotment, as their friends renovated the community house, played cards or lifted weights.

of the interview, if and when required. The process of dialogue was often continued after the full 90 minutes of tape had been used, as we gathered together for community activities and the continued renovation of the community house.

In time, this process brought me back to London, to find teaching work and begin the classification and coding of transcripts. (To say that this data filled the whole of my room, would be an understatement of the magnitude of the task.) The process also involved months of typing, as I was determined to include, for example, every pause of the interviewee, believing that often these, in themselves, speak louder than words.

(Two examples of these transcripts are included, with the permission of the interviewees, in the appendices of this thesis.)

It is important to emphasise here, that Grounded Theory Methodology serves to generate theory, rather than simply verify it. The two activities are not divorced; but should be seen in relation to their place in the larger part of the entire research process.

The verification of theory, for example, is too often formulated and generated by 'logical' deductions and priori assumptions (Glaser, Strauss); whereas Grounded Theory involves the discovery of theory through data, itself. For example, a major strategy of Grounded Theory is that of comparative analysis. Through a process of collecting, coding and analysing data, categories of research/ theory are then discovered and presented for future examination and interpretation.

Such modules of research theory can then act as 'building blocks' to the foundation of overall research in that specific subject-area. As one 'block' of research is then placed beside (or upon) another, a framework of theory can develop. It is from here that future research predictions and recommendations can be made, that are not only relevant, but applicable and pertinent to the findings, as expressed by the qualitative source of data.

Format

I will divide the following piece of research into four distinct chapter/modules, which will collectively meet the proposed aims of this thesis, while generating small 'building blocks' of theory, which could act as a basic

foundation for future research.

In the first chapter, I will present some of the education theory of Brazilian educationalist, Paulo Freire (1972), introducing his concepts of the 'culture of silence', and 'problem posing education'; his critical-reflection praxis and the processes by which we can all emerge from this culture of silence, to find our voice and achieve our own process of 'conscientisation', in relation to all three epidemics.

I will also describe the developing HIV/AIDS education praxis of the community Stand Up Harlem, New York.

In so doing, I will introduce the voices of those emerging from its own critical-reflection praxis, determined to live and educate positively as to their own personal reality of living with the virus/syndrome; while developing a culture of meaning and resistance to the myths, prejudice and stigma, so often associated with HIV and AIDS.

In the second chapter of this thesis, I will introduce the work of Brazilian theatre maker, educationalist and political activist, Augusto Boal; briefly examining his pedagogy pertaining to the Theatre of the Oppressed, (Forum Theatre, Invisible and Image Theatre) and the concepts by which we can educate (and be educated), out of our own personalised culture of silence, to find our voice and demythicise our own reality.

I will briefly look at the work of drama educationalist, David Diamond and discuss the work of Tania, an educator presently living with the virus and teaching in the schools of London, England. (1994).

I will define the difference between information and education campaigns and introduce some of the findings of the British National AIDS Trust Youth Initiative, (1991), which includes the voices of students as they emphasise the need for HIV/AIDS education in their schools, and their enthusiasm to be involved as part of the developing praxis.

In the third chapter, I will further discuss the nature of the HIV/AIDS epidemics as defined by Dr Jonathan Mann, founder of the World Health Organisation Global Programme on AIDS. The emphasis of the discussion will be on the fact that we are all affected by the third epidemic; whether we are living with the virus, affected by the virus, educating as to the realities of the virus; or simply choosing to believe that it does not exist.

This chapter will include the voice and experience of Byron, a New Zealander presently living with the virus in London, and some of the ways the government and media have influenced our perceptions of the first two epidemics; adding to the fear and repercussions of the third. I will also include in this chapter, just some of the examples of excellent HIV/AIDS education praxis presently being developed in Aotearoa/New Zealand. I will define the difference between sex and sexuality education and look to the research findings of New Zealanders Gillian Tasker (1992) and Forrest Chambers(1991-93); which indicate that there is not only parent/teacher/student approval for the development of HIV/AIDS education praxis in the schools of Aotearoa, but an urgent need for the government of New Zealand to provide the finance and education resources so necessary for its implementation.

In this third chapter, I will also use a Freirian analysis to illustrate that it is important, in both the development of HIV/AIDS praxis and education policy/legislation, to see our schools as consisting of (parent, teacher and student) communities, all capable of networking among the larger national community of (parents, teachers and students), in order to lobby for policy development that will ensure the long-term effectiveness of their education praxis.

The fourth chapter will continue the Freirian analysis to illustrate the ineffectiveness of merely *informing* our young people as to the facts of the first two epidemics; as opposed to *educating* them as to the realities of all three. I will include here, the voiced experience of Richard and Lucy (New York, 1993); the research findings of Cindy Patton (1990), Peter Aggleton, Hilary Homans (1988) and the voiced concerns of those participating in the British National AIDS Trust, Living for Tomorrow Youth Initiative (1990).

This chapter will also discuss the work of New Zealander, Geraldine McDonald (1994) and the research of Felicity De Motto of the University of London (1994); with the latter emphasising the need to further develop peer education among our young people, in relation to all three epidemics.

Finally, I would like to emphasise, throughout this thesis, the need for all of us to find our own voice, network with those we most identify and enter into our own process of conscientisation, in order to demythicise the reality of HIV/AIDS; developing the education policy we need to ensure the long-term effectiveness of our own respective HIV/AIDS education praxis.

Terminology

A full Glossary of HIV/AIDS terminology is included, together with a review of the literature, in the appendices of this thesis.

I would like to establish from the onset, the definitions of the following terms:

1. HIV refers to the Human Immunodeficiency Virus.

It is the virus that *can* lead to the development of AIDS. But this is not always the case. Many of those interviewed in the course of this research process, have been living with asymptomatic HIV for 9-13 years. (No symptoms of illness.) These people no longer drink, drug or smoke. They sleep well, eat well and avoid all unnecessary stress.

HIV can, of course, give rise to many symptoms and conditdions of which AIDS only represents a part.

2. AIDS refers to Acquired Immunodeficiency Syndrome.

This term was first coined by the Federal Centres for Disease Control (CDCs) in 1982. There has, however, been much debate over the correct usage of the term. Much has been learned about this disorder in recent years, but still much is to be deciphered. We do know that it is an infectious syndrome, characterised by the weakening of the body's immune system. By 'infectious' I mean that the syndrome can develop eventually from the transmission of the HIV virus, via blood and semen. Its effects may vary, from individual to individual, but once the syndrome has developed it is generally progressive and debilitating.

3. The names Aotearoa and New Zealand will be used interchangeably in the writing of this thesis. Aotearoa is the original name of this country. New Zealand is the European given name. Both names are official.

'You know...my friend always tells me: "Charlene, you've watched all your friends die. Now, you're watching your daughter's father die. And one day, you're going to die. Are you going to die this way? Are you going to *suffer*?"

And today, I did the *AIDS quilt*. And the [people] were like: 'Well, you can have this little space - [for a memorial panel] And I was like: ' I wanna twelve-by-twelve.'
' Cause I've lost so many people to this disease, you know. And I want the world to *know*...this is *what's* happening.'

Charlene (23)
Harlem, NY, 1993.

Questioning the Culture of Silence

'Rather than being encouraged and equipped to know and respond to the concrete realities of their world, they were kept 'submerged' in a situation in which such critical awareness and response were practically impossible and it became clear to [them] that the whole education system was one of the major instruments for maintaining this culture of silence.' (1)

Paulo Freire, Brazilian writer and educationalist, is well known for his liberation philosophy and methodology, of literacy education for the dispossessed of South America. (Freire, 1972) Having been thrust into poverty at an early age, Freire vowed to dedicate his life to the impoverished, the oppressed; those who, like himself, had been submerged into what he later came to describe as the 'culture of silence' of the dispossessed.

Freire came to believe that the silence, the apathy, the apparent inability of the stigmatised to find their voice and confront their oppressors, were all the 'direct product of the whole situation of economic, social and political domination - and of paternalism - of which they were victims'. (2) And that, as 'victims', they were kept 'submerged' in situations where they were, in fact, rendered voiceless.

Freire, developed a pedagogy which encouraged dialogical encounters among peasants who, in collectively discussing their daily routines and concerns, provided the literary themes (and the later generative themes), of their own literacy education. Through an active process of dialogue and reflection, the peasants gained a new sense of self, and became conscious of their own personal perceptions of reality; so as to deal critically and constructively with it.

It is here, that Freire introduces us to what he terms as the process of 'conscientisation'. As the oppressed, for example, step out of isolation to further examine their own personal and social realities, they move with the creative liberating dialogue, which takes them out of isolation; through to critical reflection/participation, and into reflective action. It is through this process of dialogue and reflection that the men and women begin to consider constructive action against the oppressive elements of their society/themselves.

In translating Freire's work, Richard Shaull defines 'conscientisation' as 'learning to perceive social, political and economic contradictions, and [the taking of] action against the oppressive elements of reality.' (Shaull, 1972)

Freire also emphasises throughout his work, that problem-posing education should not only demythicise reality, but also serve to 'affirm men [and women] as beings who transcend themselves';(3) it is a humanist and liberating practice;(4) the oppressed should not, in turn become oppressors; (5) they realise their own liberating and human potential;(6) they come to see the world not as a static reality, but as a reality in process, in transformation;(7) with education ultimately being 'a practice of freedom - as opposed to education as a practice of domination'. (8)

Freire totally opposes what he came to term, the 'banking concept' of education. This is the process by which teachers (as subjects), deposit knowledge into their students (the objects). The task of the objects, being that of passively accepting, filing and storing the deposits. Only to just as passively regurgitate them, as required.

Freire believes that education, in general, is suffering from 'narration sickness' (9) and that concepts of conscientisation and action-reflection praxis, apply equally well to the so-called countries of the 'first world' as they do to those of the 'third'. Or, at least, there are to be found many similarities and parallels. For, as Freire insists:

'There is no such thing as a *neutral* education process. Education either functions as an instrument which is used to facilitate the integration of the younger generation into the logic of the present system and bring about conformity to it;

or it becomes "the practice of freedom"; the means by which men and women deal critically and creatively with reality and discover how to participate in the transformation of their world.' (10)

[Emphasis of Freire]

Paulo Freire's philosophy can, (and has been), translated by the peoples of many societies, into a pedagogy that suits the specific cultural and social needs of its people. It is essential to emphasise, here, that many societies (especially those of indigenous peoples), have in fact, been practising the type of philosophy Freire espouses for many centuries anyway. But equally as many indigenous groupings have often lost their voice, their traditional ways, to the violence and assimilation of the invaders/settlers of their homelands.⁵

Freire's pedagogy of the oppressed is relevant today, in serving to encourage the oppressed, to enter into dialogue and critically reflect on their own immediate and personal realities, so that from the beginning the oppressed themselves, may be the subject of their own transformation; creating their own action-reflection praxis, while bringing to life again, the reality of a people who once lived proud, holistic cycles of well-being.

⁵ Violence and assimilation being synonymous, when one considers the loss of culture, homeland and language, that the oppressed are all too often forced to experience by the law of their oppressors.

Freire's pedagogy does not, of course, apply only to literacy education. Literacy education among the peasants of Brazil, was simply one basis from which the peasants could finally meet, enter into dialogue, reflect and act upon their own realit(ies), with the new skills they had acquired.

In another culture, language itself, might be the basis of the pedagogy. That is, a people might wish to rediscover the language of their ancestors. It could, after all, be more empowering for a people, to regain the knowledge of their own tongue; than to learn the 'appropriate' literacy skills of their oppressor.⁶

Similarly, a whole society (or groups within that society), might find the need of a pedagogy (or pedagogies), by which they can critically reflect upon the role of the oppressor, while questioning the culture of silence that so often tends to submerge those living with HIV and AIDS.

Stand Up Harlem

Stand Up Harlem, New York, is one example of a community that has developed its own philosophy (and later pedagogy) of the people, for the people, in order to challenge the silence and stigma, so often associated with HIV and AIDS.

Stand Up Harlem is a community house, offering transitional housing and support services to people who are homeless, seeking recovery from addiction and HIV. It is a self-help, peer-oriented, gay, straight, multicultural, bilingual and holistic community. It was founded by Louis Jones, himself a recovering addict, living with the virus; and Paula Palmateer, an executive from Vail, Colorado. Together they managed to come up with enough money to buy an abandoned 19th century brownstone house, on 130th Street, Manhattan. Along with community friends and the homeless, they began to renovate the rooms for those coming off the streets, in need of support and recovery information.

In the summer of 1992, I arrived in Harlem, as a group of about 16 international volunteers, to help renovate (in a small way), some of the community house. We were immediately welcomed as part of the community. And were encouraged to be part of all community meetings and activities. During this time we were fortunate enough to watch

⁶ The theft of language, in the form of assimilation, being a subtle but equally violent tool of the oppressor; in that once a language is slowly lost, generation by generation, so too are the stories, the oral history, the culture; the very spirit of the people.

the developing philosophy that was to become the fundamental foundation of Stand Up Harlem; a philosophy, not unlike Freire's, but specifically dealing with the culture of silence surrounding homelessness, addiction, HIV and AIDS.

It was through a process of dialogical encounters and critical reflection praxis, that the community began to voice its concerns and moved into action; challenging the silence that had surrounded, for so long, their very existence.

In the summer of 1992, I was handed the following community document, which we often read in group meetings to remind us of our group philosophy and purpose. It also encouraged us to find our voice (silence=death); to stand up and break the silence-cycles of poverty; while challenging the myths and stigma surrounding HIV and AIDS.

The original document reads as follows:

STAND UP HARLEM COMMUNITY HOUSE

OUR CONCERN is that members within our community are living without homes, addicted and with AIDS, living in fear, isolation and neglect.

OUR CONVICTION is that this is intolerable.

OUR COMMITMENT is to the empowerment of our people within the community.

WE STAND UP challenging the social stigma of race, homelessness, addiction and AIDS.

WE STAND UP breaking silence (silence=death)

WE STAND UP demanding our human rights.

WE STANDUP taking charge of our lives, for our lives; helping ourselves while helping others.

WE SURVIVE and THRIVE in Harlem, living in loving support of one another.

WE STRUGGLE in Harlem, being empowered, taking control of our LIVES, the LAND and the LOTS.

WE PRESSURE in Harlem, for HOUSING, HEALTH CARE, TREATMENT, AIDS education and prevention.

WE SUPPORT all efforts to end 'the crisis' in communities of color.

WE CONFRONT any opposition to these efforts.

We are of the community, for the community, by the community, a community of HELP, HOPE, and HEALING.

STAND UP HARLEM

This document clearly illustrates the group philosophy and commitment to recovery from addiction, HIV and AIDS.

It also draws to attention, several major interrelated issues that were (and are) inseparable from the focal issue of recovery, when considering the pervading cycles of poverty, lack of land, health care and housing, among communities of colour. Those involved in the emerging community of Stand Up Harlem had clearly spent time,

working through their own process of dialogue; reflecting on their own personal and collective experiences, and had begun to emerge from their process of conscientisation, to take action against the oppressive elements of their own immediate reality.

Choosing to be called by the very name '*Stand Up*' is indication, in itself, of the empowerment experienced by those planting the first seeds of a pedagogy, that would soon become a literal practice of hope and freedom, among the peoples of mid-Harlem. The name too, implies a certain strength, a call for the humanisation of a dehumanised society; a sense of coercion in confronting the culture of silence that has draped itself, like a veil over communities of colour and those who have lost their voices to the hopelessness of addiction. But '*Stand Up Harlem*' also invokes the sound and voice of an older memory to emerge, which will confront the many smouldering, intolerable issues of poverty and neglect that existed (and still exist), long before the pandemic of HIV and AIDS ever became an issue in Harlem's own community.

Charlene, for example, points out (during a discussion in the summer of 1993), the dichotomy that has emerged among peoples of colour, as a direct result of a larger oppressed society:

'...You know what's even more scary...[than HIV] ?
I mean, *let alone* that we have cancer. We have tuberculosis. We have all these troubles...out here. And still we feed *each other* with drugs. [pause] We kill our brother man. Black. White. Chinese. Puerto Rican. We kill *each other*. We take *each other* out. Haven't we had enough to fight? Haven't we enough things, out there, to go against us?'

Charlene, 23 [Interviewee's own emphasis.]

Charlene's reflection upon her own reality and that of her society, makes pertinent just one of many underlying issues brought to the surface of discussion, as a result of her own action-reflection praxis. It is a call for unity, especially among peoples of colour, to work not only in the fight against HIV and AIDS, but in the very unveiling of issues, directly related to the structures of oppression that still maintain the culture of silence surrounding it.

The original founders of *Stand Up* certainly chose to put their dialogue and reflection into practice from the onset. As recovering addicts, many of us continued renovating the downstairs section of 145 West, 130th Street, while the original squatters of the building, continued to run their upstairs crack (cocaine) business. Rather than evict them, Louis Jones (now Director of *Stand Up Harlem*), together with his colleagues, chose to continue the recovery programme downstairs and encouraged the addicts upstairs, to join rehabilitation programmes.

The work of Stand Up and its community rapidly reached (by word-of-mouth), the wider communities of Manhattan and by September 1992, the organisation was awarded (US) \$168,000 from the Ryan White Title (I) appropriation made to New York City. In November 1992, a second award (\$ 462,000 US) was allocated to the community for transitional housing, in recognition of its outstanding work and to cope with the influx of homeless people seeking recovery and support for HIV and AIDS.

This is not to say that things came easily to Stand Up Harlem. There were (and still are), many days and weeks of extreme stress and hardship. The fact that Stand Up has received two prestigious grants, was/is certainly useful in the short term, but it says little for a society(ies) that has/have taken almost 15 years to acknowledge that an epidemic is still wiping out whole generations of peoples, who were previously (and still are), considered 'unworthy' of attention. It says little of the general apathetic attitude and lack of action on the part of whole governments who, from the onset could have curtailed this pandemic. For, as Dr Mathilde Krim, the founding co-chair of the American Foundation for AIDS Research has consistently pointed out:

'This is an epidemic that could have been contained. Everything about this epidemic has been utterly predictable, from the very beginning, from the very first day. But no one would listen. There are many people who knew exactly what was happening, what would happen and has happened, but no one of any importance would listen. They still won't listen. We definitely could have contained it.' (11)

Prestigious grants are, of course, received with gratitude. But perhaps only serve to cast yet another shadow of tokenism over the real costs of this epidemic. For, should not the governments of our respective countries have been, taking at least a financial responsibility for what they could see was a potential pandemic, as early as 1982? The truth of the matter is, they were not interested.

The actual original naming of the AIDS syndrome, speaks for itself: GRID5. From the very onset, the virus and syndrome were dubbed 'Gay Related Disease'. And the governments of most countries have demonstrated quite well (and continue to do so alongside the misinformation and hype, fed to us by the media and press), that the gay community is not in the least bit, an object of their concern. Neither are addicts, or communities of colour.

By 1982, the syndrome was re-named AIDS: (Acquired Immune Deficiency Syndrome), but the moralistic stance of our governments continued (and continues), to accentuate and perpetuate the myths and stigma, still so wrongly (and

inaccurately), associated with the virus and syndrome.

Prestigious grants often also serve to keep powerfully developing communities in their 'rightful' place, ie subservient to the hierarchy that holds and controls the proverbial purse-strings. This was definitely not the case of the awards granted Stand Up Harlem, but has been the case of many other communities who have demonstrated a willingness and unity in tackling the problems, that their respective governments have chosen to ignore or simply negate.

Humanists or Humanitarians: The Building of a Community Health Education Praxis

In order to develop effective and culturally sensitive HIV/AIDS education praxis, we must each assess our own place in the epidemic(s) and partake in our own continued process of conscientisation.

With regards to developing such a praxis, we seriously need *humanists* as opposed to *humanitarians*.

Freire wrote, long ago, of society's need to transcend the oppressive nature of the 'giver' (as subject) and the 'receiver' (as the perpetually grateful object). (Freire, 1972)

For, all too often, humanitarians will work alongside of the 'oppressed', expecting the oppressed to be grateful for their apparent gift of 'transcendence', without ever questioning whether they are, in fact, acting out of generosity or egotism.

Freire would suggest that 'those who authentically commit themselves to the people, must re-examine themselves constantly'.(12) And that 'Our converts...[the humanitarians]...truly desire to transform the unjust order; but [unfortunately], because of their background, believe that they must be the executors of the transformation'. (13)

The community of Stand Up Harlem, believes that it is essentially the people, themselves (addicts and/or those living with the virus), who must develop their own action-reflection praxis and become the subject of their own process of conscientisation.

Stand Up Harlem has an open-door policy to all who find their way to its community. All are welcomed-in, from the onset, as part of the 'family' and many choose to identify with it, as such: That is, not only as a source of

information and support, but one of laughter, strength and encouragement, as individuals venture out again into programmes and activities that they (by choice), pursue in attempting to meet their own recovery needs.

Stand Up Harlem keeps its central focus on the specific needs of the Black and Hispanic communities; always endeavouring to reawaken in individuals, the sense of dignity and pride, often lost over the years, to conditions of extreme poverty, addiction and racism.

‘The truth is...the oppressed are not marginals...living “outside” society...The solution is not to “integrate” them into the structure of oppression, but to transform that structure so that they can become “beings for themselves”. (14)

The community of Stand Up serves to empower addicts and people of colour to use their own background/s and/or sexual orientation, as a focus of identity, from which they can gain the fundamental strength and action-reflection praxis to become the executors of their own transformation.

For what, after all, are the real costs of this epidemic, when one considers the appalling lack of government initiative in planning HIV/AIDS education, for our so-called ‘marginalised’ communities? It certainly cannot be measured in financial terms. Charlene could undoubtedly be speaking for thousands of others, when she describes the experience of receiving her sero-positive diagnosis:

‘..So, I came in [to the clinic] And the doctor told me. That I was positive. And that it was OK to cry. And that was it.

You know, “It’s OK to cry, Miss C -” And it was like, real plain and simple. [pause] So I cried.

I cried. And I didn’t know why I was crying. I didn’t know what the disease *was*. I didn’t know what I was crying for. I just knew I had [pause] *something*. And they didn’t have a cure for it.

I didn’t know that people were dying all over the *world*; that my generation was being wiped out [pause] from AIDS.’

Charlene, 23 [interviewee’s emphasis]

The very fact that Stand Up Harlem has emerged from the community, as such a source of inspiration and strength for its peoples, is becoming increasingly well publicised in New York City, (1994). The facts of its origins, however, (the stress and hardships it endured and still endures), as it continues to develop its HIV/AIDS education programmes for living positively with the virus/syndrome, are certainly less well advertised.

Joe, 27, an addict coming to terms with his own sero-positivity, describes his own first impressions of Stand Up, in the summer of 1993.

(Note: This is one year *after* the completion of the original renovations, initially described of July/August 1992.)

Joe: Well, I just didn't know what the fuck it was man. [Stand Up Harlem] I was like [pause] "what am I doing here?" You know. I just thought it was some kind of shelter...

At night, I'm waiting to go downstairs, and go to sleep, you know, 'cause I thought you went downstairs. And there were [maybe] beds for you to sleep. And like, I see everybody carrying their beds *up* from downstairs. And I'd like...[pause]

At first, when I came here, I didn't have too much faith in it. Because of the appearance - '

Catriana: What was the appearance like?

Joe: Well...the appearance was [pause] run down. I was like: "What *is* this place?" And you know the day-room, turns into the dining room. And the dining room turns into the sleeping room. And it's like, the same room, turning into different things...Into the movie room; and it turns into the hang-out room. And it's like the same [laugh] fucking room.

And I [was confused]...I thought "What the hell is this -?" Are things going to start coming out of the walls, like an aeroplane, you know? Are oxygen tanks going to come out of the ceiling, if there's a fire? I don't know. But it was like [pause] these people are so *poor*. [pause] Can you tell me, what's going on here? But [pause] everything turned out OK.'

[Interviewee's emphasis]

The physical difficulties of co-existing in such a small space were certainly extreme, given the overcrowded conditions; the fact that there was only one toilet, one shower and all the cooking (for 30+ people) was also prepared in Joe's proverbial 'day-room'. There was, by this stage however, heat and electricity; with longer-term residents being now able to sleep (4+) to a cubic room, a little further upstairs.

Tai' Chi, acupuncture and day groups were also well underway; with the evening AA and NA groups thriving on the energy of people's survival stories and shared experience.

The days, themselves, were always begun with breakfast, followed by a community meeting (8am), lasting half an hour which usually included readings from the '12 step programme'; listings of the day's events and workshops; (an example of a typical weekday programme being on the following page) and the session usually ended in personal and community news, followed by laughter and often song.

It was during this time, that evening and weekend outings were also announced. And as long as addicts, new to the

8:30 Morning Gathering **END OF SECOND WORK**
9:00 T'ai Chi **CAMP**

11:00 Intervention Team Meeting

Noon Lunch

Hospitality 1 - 5 PM

Acupuncture 1 - 4 PM

2- 3:30 Women's Support Group (in-house)

6:00 Dinner

6:30 Significantly Affected

TUESDAY

7:45 Breakfast

8:30 Morning Gathering

9:00 T'ai Chi

10:00 Recovery Readiness

Noon Lunch

Acupuncture 1 - 4 PM

6:00 Dinner

7:00 HIV/PLWA Women's Support Group

7:30 **METS BASEBALL GAME**

WEDNESDAY

7:45 Breakfast

8:30 Morning Gathering

9:00 T'ai Chi

Noon Lunch

1:00 AA Meeting Hospitality 1 - 5 PM

3:00 Guest Orientation

6:00 Dinner

7:00 LAP - HIV Lesbian Women's Support Group

7:30 **A BETTER LIFE - Theater Row Theater**

8:30 - 9:30 Independent Living Group - Transition

8:30 Morning Gathering

9:00 T'ai Chi

10:00 Transition Team Meeting (1) - House
ALIVE WITH AIDS

Noon Lunch

1:00 Transition Team Meeting

2:00 - 3:00 Peer Support Focus meeting

3:00 Team Meeting

Acupuncture 1 - 4 PM

4:00 Group Facilitators Focus Meeting

6:00 Dinner

7:00 Gay Men of Color

7:30 PA Meeting

FRIDAY

7:45 Breakfast

8:30 Morning Gathering

9:00 T'ai Chi

LINKING HANDS

(AIDS) Rally 10 - 2
Harlem State Office
Building

Noon Lunch

Hospitality 1 - 5 PM - **Agency Food
Distribution**

Nurses's Station 1 - 5 PM

3:00 - 4:00 Day Hospitality Focus mtg.

6:00 Dinner

7:00 G & L NA Meeting

SATURDAY

10:30 Brunch

**Summer Youth Boost Program
Tour of Apollo**

5:00 Dinner

1:15 - 3:00

SUNDAY

10:30 Brunch

4:30 Dinner

6:00 NA Meeting

AIDS Quilt Project

1:00 - 5:00 P.M.

community, had spent the first provisional seven days on the premises, all were offered the occasional opportunity of free sets of tickets to Broadway shows, TV talkbacks and recovery dances, Downtown; not to mention the many other happy opportunities we experienced together, being crazier than anything we'd ever seen in Central Park.

The action-reflection praxis of Stand Up Harlem includes giving people the chance to see how well and positively we can all live with the virus, whether directly infected or affected by the epidemic(s). It gives people the chance to find their voice(s) again. Or, as in the case of many who arrive at the doors of Stand Up, allows individuals to come to the realisation (often for the very first time), that they have a voice at all. The community also encourages many recreational activities and the chance for individuals to opt out of meetings and activities, if they feel that they need time and space to assimilate all that they have been seeing and hearing. At Stand Up, *laughter* is also considered an essential part of recovery; as are the tears. And often newcomers-to-organisers, can be seen dealing with both, in a variety of ways; from lifting weights in the back yard, to having (or attempting to have) , a quiet cigarette on the outside stoop.

Joe, himself (previously cited), speaks further of his impressions of Stand Up Harlem, in the interview of August 1993, whereby on having described his initial reaction to the physical hardships of the community, he goes on to emphasise, what he sees as the value of its action-reflection praxis:

'...Before I came here, to Stand Up...I stood in the streets for three days. I thought it was going to be the end of the world for me. I thought "That's it. I am going to die." At that point I had no money. I hadn't eaten. I couldn't get high...

[But] then I started taking it in, [the recovery programme of Stand Up], one day at a time, you know. I started feeling better and better, day after day. [pause]

And now I started meeting all the people. And the director. And the international volunteers. I have friends now. I can talk to people. And the meetings are really good. [pause]

...The recreation stuff, they have, like Tai 'Chi and the acupuncture...And this all good stuff. And like, it really *shocked* me...You're not really supposed to judge a book by its cover, you know. But that was what I did, when I came here. And then, as days went by, I found out that there's really [pause] fabulous things happening here. Very [pause] fabulous people. And people that care. People that love me, you know. I really feel good now, about the place.

I like the recovery meetings. And the hospitality times. Just everything, you know. I like everything. The volunteers are really cool, you know. [pause] I'm gonna miss them, when they leave. But everything's just great...I just focus on what I'm doing, which is [pause] succeeding at my recovery.'

Joe, 27 [Interviewee's emphasis]

Many of the other residents of Stand Up, also wished to describe their views of the community and how they have not only come to accept their addiction and sero-positive diagnosis, but how they have, in fact, come to live life more fully, as a consequence.

‘I wish there could be a [Stand Up] like every ten blocks. Because it’s needed. It’s really needed. And [pause]...working here, to me, is a...powerful example to other women. Because...[it] helps not only being HIV positive, but [with] being an addict in recovery, as well.

This community is the closest thing really, to independent living. Basically, everyone taking care of their own needs. Except there are certain things we do together, like have our meals together. AA and NA meetings together. We laugh together. Cry together. We go through our ups and downs together.

You know, nobody has to go through any pain or suffering here, *alone*. And that’s one thing I learned here, at Stand Up. You don’t have to *suffer*. All the craziness in the world, going on around me. I don’t have to live like I lived before.’

Phylis, 40 [Interviewee’s emphasis]

Hanif, who has been living with HIV for 8 years, also describes his sense of empowerment, as he moved out from his former culture of silence, to not only reach those living with the isolation of the virus, but to effectively challenge all those who remain submerged in the stigma, prejudice and mythology surrounding the epidemic(s):

‘I learned through my personal struggles. I learned that the HIV virus is really a weak virus. [pause] [We] can live a normal life...Since I’ve been [diagnosed] HIV positive it [Stand Up] gave me a new outlook on life. As far as awareness. As far as willingness. As far as striving.

I just spread the message to other people, as far as being a living trophy; to prove to people [who] are not much aware of it... in New York or Brooklyn. And family members...that a person who [has] HIV, don’t have to be [pause] sick. [Or] *bedridden*, [or] confined to a room. [We] don’t have to be isolated. [We] can live a normal life. [We] can. [We] can be amongst you, without you even detecting it...I call myself, right now, a long-term survivor.’

Hanif, 35 [interviewee’s emphasis]

This is not to say that all people found it easy to approach, let alone *trust* Stand Up, as a positive place of recovery, from the onset. The culture of silence that had, for so long, surrounded persons living with the virus, had not only kept them dehumanised and voiceless; it had in many cases, rendered them virtually crippled in seeking out the support and attention they so desperately required.

Many addicts, for example, on having decided to seek advice and support, have simply recoiled into their former silence, when finally services have been available to them. They speak of the constant climate of fear and mistrust they experience, in trying to cope with racist and homophobic attitudes of a society which still holds close to its heart, such archaic assumptions of HIV /AIDS and addiction.

Howard, 26, himself a recovering addict, describes how difficult it was to come to Stand Up Harlem; to trust any organisation, especially with respect to his sero-positive 'status':

'This friend of mine, told me about this place. [Stand Up Harlem] But, I was too scared to come here. I was afraid. I said to him: "The only way I'll go, is if you will take me. And if they treat me any differently, I'm out the door, that same night."

I'd rather live on the street, [than be treated like that]. Then I wouldn't have to worry...about other people. Because they just wouldn't care. You know. No one would care. Well [they'd think] like: 'Well, he's just another alcoholic bum. He's just another homeless person. Who cares?' That would be their attitude. So, they wouldn't treat me any differently. They wouldn't know I have HIV."

Howard, 26 [Interviewee's emphasis]

In so many ways, Howard's statement of apprehension and self-depreciation, indicates just how deeply ingrained the stigma and prejudice has become, for those trying to live in their societies with their sero-positive 'diagnosis'. Equally as horrifying (for anyone who has seen the extreme conditions of poverty and malnutrition suffered by the homeless, 'living' on the streets of New York), is the fact that Howard (and many others like Howard), come to prefer the option of being swallowed up by the silence of homelessness as a more 'tolerable' solution, than having to deal with society's blatant prejudice and dehumanisation of those living with HIV and AIDS.

Let me emphasise here that Howard is, in no way, idealising the situation of being 'homeless'. He, along with many of those seeking assistance from Stand Up Harlem, has experienced directly, the degradation of living on the streets; and all have equally horrifying accounts of their survival. The reality is, society has too often perpetuated the myths and accentuated the stigma of sero-positivity, and in so doing, has effectively left peoples as outcasts even (and especially) to their own community of peoples. It is not surprising then, that wider and wider cycles of poverty and dehumanisation are being reincarnated, as a result of society's ignorant reactions to the pandemic. Neither should it be surprising that those abandoned by society, are beginning to differentiate between developing cycles of 'outcasts'

in attempting to live (as one newcomer to Stand Up described), on the outer-most rings of a twentieth century rendition of Dante's hell.

The voice of Howard also brings to mind, Freire's (1972) observation of the process of covert violence, reemerging in the form of dehumanisation, on the part of the oppressor:

'Self-depreciation is another characteristic of the oppressed, which derives from their internalisation of the opinion[that] the oppressors hold of them.' (15)

The fact that Stand Up chooses to deal specifically with this level of depreciation, alongside the immediate physical needs of individuals, as they literally walk through the doors, is something that has an empowering effect, even on the most cynical, as they gradually choose to become part of its action-reflection praxis:

'It was very difficult for me, to deal with HIV. It was hard to deal with. I didn't want to be HIV positive. But, I learned how to live with it. And if it wasn't for this place here [Stand Up], [pause] I don't think I'd be living with it, right now. I would've continued to use drugs. I would've said: "Forget it. What the hell. I'm going to die anyway-"

But here, [at Stand Up], they gave me love and support. Gave me an education about it. And man, hey, I'm fine about it. I can live with it."

Howard, 26

More telling, however, is an account given as Phylis walks in on our August 1993 interview. Phylis (previously cited), was by now, the intervention/transition coordinator at Stand Up. Howard agrees with the description she gives of him, on entering the community and the empowerment he has experienced since coming out of isolation, to live positively with his original HIV diagnosis:

Phylis: Tell her [Catriana] how you were, when you first arrived here [at Stand Up].

Howard: Angry?

Phylis: Angry. [pause] Howard was counter-productive to Howard. Howard didn't want to hear it. He didn't want to do it [the programme]; he didn't want to be here. [smile] *Howard*. He just wanted to be left alone. Howard didn't like people. Howard didn't like anything. Name it: Howard didn't like it. He didn't like making meetings. He wanted to be part of; but he didn't *like* being part of. Howard was lonely. But he wasn't alone. Only by choice.
He [Howard] had a *real* tough time, accepting his 'diagnosis' as being HIV positive.

Howard: Sure did.

Phylis: It made him crazy, you know. He was very bitter. And at [Stand Up] I guess, living with people, who were [also] HIV positive...knowing that he wasn't alone [helped], knowing there was nothing he could do [about his sero-positivity], if he was going to live with the virus. *That he was* going to live with the virus. And he made a complete turn-around. His attitude changed. He became...accepting. His awareness was heightened.

And in return, he gave it back, to the newcomer, coming in. You know, he would meet them at the door. And let them know, it was OK to cry. It's OK to be afraid. Then he would share his experience, strength and hope.
Howard, he's really something. I think of him, like my son.

[Interviewees' emphasis]

Direct parallels, then can be made between the praxis of Stand Up Harlem and the pedagogy of Paulo Freire.

Through a process of dialogical encounters, Howard came to reflect (as do many others at Stand Up), upon his own reality, and the perceptions on recovery, of those around him. The perceptions of those around him were not (and are not), of course, essential to his own self-determination. But they served to act as a resource for his own critical and positive self-reflection. Once the perceptions of others are acknowledged, they can equally well, be left to one side, as mere tools of his own action-reflection praxis.

We are, after all, not talking of individuals being 'transformed' into someone else's reality, but rather, individuals being given the chance to seek out and listen to those with whom they most identify, in order to gain the constructive and loving support they need to transcend the grief and isolation, so often internalised by months and years of trying to survive society's reaction/inaction to the virus and the syndrome.

Lucy, 40, reconfirms the positive sense of recovery and empowerment, experienced by so many, living in the community of Stand Up Harlem with the following statement:

'When I got out of jail, Stand Up Harlem seemed *crazy*. [pause] When I came in here I was scared...All these men and women around. You know, there's an awful lot of people there. Like, *what* have I got myself into?

[But] when I came over here [to Stand Up], they treated me like: " Well, you're one of us," [pause] and "If nobody has told you they love you, today, we love you."

...And that made me feel [pause] needed...And I have a lot of help with HIV, because [now] I always *eat* right. Sleep right. And you just wanna keep trying it, every morning.
Today, I have a lot of gratitude in my heart, because I'm still *alive* and *kicking*; still going strong...I know a lot of people who [have] HIV. And they're still in denial. By 'denial' I mean, they still haven't accepted it. They haven't loved themselves, that much yet.'

Lucy, 40 [Interviewee's emphasis]

For too long now, 100,000s of people like Lucy, throughout the world, have been kept submerged in a culture of silence surrounding their sero-positivity, that has rendered them virtually voiceless. Lucy has, finally found her voice. And through their own process of conscientisation so have Howard, Hanif, Charlene, Joe, Phylis and countless others in this tiny, but growing community, on the forgotten streets of Harlem, New York. They are no longer 'marginalised' victims of the HIV virus and AIDS syndrome; but are now, by their own self-determination, moving out into their respective communities, to encourage dialogical encounters among peoples who will, in turn, act upon and transform their own realities and concept(s) of self.

Stand Up Harlem is 'alive and kicking', and more than prepared to meet society's ignorance and indifference, with their own empowering pedagogy and practice of freedom.

In planting the seeds of his 'literacy' pedagogy, among the forgotten of Brazil, Freire (1972), once cited the voice of a peasant, who after only a few days of action-reflection praxis, joyfully announced: "I now realise I'm a[hu]man". While another proclaimed: "Before this, words meant nothing to me; now they speak to me; and I can make them speak."(16)

Twenty years later, echoes of a similar pedagogy, developed by its own community, can be heard from the mouths and lives of the Black and Hispanic peoples of Manhattan:

'I have knowledge in my head now. But, I have the best knowledge of all. And that's that I have a Masters in Streetology. Streetology is *knowing* what's out there on the streets: knowing what drugs did. Knowing what rapists did to me. Knowing what incest did to me. Knowing what HIV did to me. And knowing that that I survived it all.
If that didn't kill me, HIV isn't going to.'

Lucy, 40 [Her emphasis]

References

1. Freire P. *Pedagogy of the Oppressed*. New York: Penguin, 1972, p10.
2. Freire P. Op cit. p10
3. Op cit. p57
4. Op cit. p58
5. Op cit. p21
6. Op cit. p30
7. Op cit. p56
8. Op cit. p54
9. Op cit. p45
10. Op cit. p13
11. Kramer L. Reports from the holocaust: the making of an AIDS activist. New York: St Martin's Press, 1981, p150.

12. Freire P. Op cit. p36.
13. Op cit. p36.
14. Op cit. p48.
15. Op cit. p38
16. Op cit. p13.

'They see me looking well. And they can't actually believe that I have the HIV virus. And the fact that I'm young. And when it sinks in a bit, they think, well...Some of the questions are:

"Don't you think you were irresponsible...I mean, you *knew* about safer sex- "

That was a very naive 16 year old boy, that said that. And I remember feeling, so shocked. I mean, I wanted to tell him: "Well you fucken wait, till you have sex. You wait, till you know what passion's about - "

And I had to say to him: I was 18. I was in my first and long-term relationship...And that, yes, if you want to be blunt about it, I am here, because I was irresponsible. I didn't use condoms. And it wasn't through lack of trying.

But I just felt like: yeah. Rub my nose in it. This is why I'm here: because I want to help you [pause] not to have to go through this, as well.'

Tania, 23, HIV/AIDS educator, London, 1994.

Demythicising Reality: Power Play and the Rainbow of Desire

‘We never try to find which solution proposed is the ‘correct’ one. I am against all dogmas. I am for people becoming conscious of the other person’s possibilities. What fascinates me about forum, is the transactive character of its pedagogy...Oppression exists, in the relationship between two persons, when dialogue becomes monologue.

The aim is to become human again, by re-establishing dialogue.’ (Augusto Boal, 1989)

Augusto Boal, theatre maker and political activist, has become increasingly well-known throughout Europe, in recent years, for his social and political vision; his aesthetic philosophy, embodied so effectively in the many dramatic techniques he has developed in his now internationally reknown, *Theatre of the Oppressed* (TO).

(Boal, 1994)

Like Freire, Boal witnessed the poverty and socio-political upheaval of his own homeland. But whereas Freire was arrested and ‘encouraged’ to leave the country, after the military coup of 1964, Boal managed to stay on, as Director of the Arena Theatre in Sao Paulo (1956-71).

It was during these years that Boal developed further, his theatre pedagogy of liberation, which encourages otherwise passive spectators, into the role of ‘spect-actors’. That is, as individuals rehearsing strategies for their own personal and social change.

One genre to emerge from the Theatre of the Oppressed, was that of the ‘Joker System’. This was a deliberate shift against the trend to found theatre on the European experience; while simultaneously challenging the theatrical conventions of Brazilian realism. The genre, itself, encourages the use of both fact and fiction; while shifting the roles within the ‘play’, so that all actors play all characters. The ‘joker’ is introduced as narrator, whose dual role is that of addressing the audience directly, as to the development of the play and the issues they might see as arising from the portrayal.

Boal had been concerned, for some time, that middle class actors were all-too-often prescribing behaviour for situations that they had never, themselves, experienced. He felt theatre could be developed further, to become a socio-

political, as well as aesthetic tool, for use among the oppressed peoples; a means by which they could individually and collectively present, express and evaluate their own concerns. In so doing, the oppressed might, in turn, achieve their own personal and political empowerment.

In time, Forum Theatre was developed. This particular genre of the Theatre of the Oppressed (TO), is defined by Boal as:

“[A Theatre of the Oppressed] technique that begins with the enactment of a scene (or anti-model) in which the protagonist tries, *unsuccessfully*, to overcome the oppression relevant to that particular audience. The joker then invites the spectators to replace the protagonist at any point in the scene, that they can imagine an alternative action that could lead to a solution. The scene is replayed numerous times, with different interventions. This results is a *dialogue* about oppression, an *examination* of alternatives, and a ‘*rehearsal*’ for real situations.” (1)
[My emphasis]

Forum theatre was to become widely used nationally and internationally, as one of Boal’s most popular theatre forms. In 1971, Boal was arrested from outside the Arena Theatre and subsequently jailed, tortured and threatened with death, should he continue to help the people ‘find their voice’ through theatre. Undeterred, Augusto Boal had, by 1973, developed what was soon to become known as Image Theatre. This consisted of a series of strategies, based on dramatic exercises, in which the participants began to create the embodiments of their feelings and experiences, without ever having to use words at all.

Another genre, that of Invisible Theatre, soon found its way out onto the streets, to stimulate debate about current community and political issues. Although, the sequence of events was rehearsed beforehand, the actors involved, moved out into non-theatrical places, ie. foodstores or crowded city streets and caught the attention of the general public, who had no idea that the sequence of events, unfolding before their very eyes was, in fact, theatre.

The performers, of course, would have to take full responsibility for whatever public reaction they received, in relation to their activity. But in most cases, Invisible Theatre usually achieved its purpose: that of stimulating lively and constructive dialogue, around the socio-political situations. It was to a certain extent, able to transcend the silencing effect of the ubiquitous ‘cop-in-the-streets’ (Boal, 1974), the ever watchful eye of the Brazilian political hierarchy.

It was, however, only a matter of time before Boal needed to urgently retreat from 'ouvert' theatrical work. In 1974, he chose to continue his writing, in order to empower those still working for the Theatre of the Oppressed. And in 1976, he left Brazil to live and work in exile, in Europe.

Theatre of the Oppressed in a Western World Context

Like Freire, Augusto Boal found it tremendously difficult, initially, to comprehend the oppression experienced by those of the so-called 'first world' societies. After all, both Freire and Boal had experienced oppression in the more ouvert forms of imprisonment, torture, extreme deprivation; not to mention the daily threats to their own lives. The discovery then, that depression, loneliness and isolation were, in fact, the areas of concern most voiced by those of the 'first world', had both educationalists respectively examining and reviewing their own pedagogies and concepts of oppression in both Europe and North America.

We know, from the history of Freire's pedagogy, that his action-reflection praxis was (and still is), very successfully used to meet the specific needs of the oppressed individuals and communities of the so-called 'first world' societies.

When reviewing the development of Boal's theatrical pedagogy, one can also see how the artist and educator began to utilise and develop his own dramatic techniques, to meet the vacuum of oppression, so often described of and by, the societies of the Western World.

As Boal became increasingly aware of the depth of pain, experienced by westerners, in direct relation to loneliness, isolation and stigmatisation of their societies, he began to develop a whole new series of dramatic methods and therapeutic techniques, soon to be incorporated into the larger, composite Theatre of the Oppressed.

These techniques became colloquially known as *Cop-in-the-Head*, and refer to that which Boal came to see as our own 'internalised cops' (Boal, 1994). These internalised cops, the ones that obstruct our wills and foster passivity, (Schutzman/Cohen-Cruz, 1994) are indeed closely related to Boal's 'Cops-in-the-Street'. And, similarly need to be addressed; perhaps even animated and given voice to, in order to challenge the underlying oppression that prevents individuals from becoming more fully accepting of themselves and their humanity.

By the 1980s, Boal's dramatic therapeutic repertoire of (TO) techniques became more commonly known as *l'arc-en-ciel du desire*. Academics and artists throughout North America and Europe, quickly became aware of these Theatre of the Oppressed techniques and worked, in close association with Boal, in developing the Rainbow of Desire to meet the specific needs of the oppressed peoples in their own communities.

Theatre of the Oppressed in Relation to HIV/AIDS Education

In response to the oppression and isolation experienced by those trying to survive positively the negativity, myths and stigma associated with the HIV/AIDS pandemic, individuals have begun to step out and collectively use the *Rainbow of Desire* to help encourage those living with the virus/syndrome, to find again their own voice, while reclaiming their own bodies, as centres of dignity and pride.

Alistair Campbell, theatre activist and co-founder of Break-Out Theatre in Education (1984), has for example, developed many of Boal's techniques, here in England, and helped establish a support network for British practitioners of the Theatre of the Oppressed. He has also worked widely with community opera and in prisons and special schools; pioneering much (TO) work, in relation to HIV and AIDS education.

David Diamond, Artistic Director of Headlines Theatre, has also played a similar role in Canada; working with refugee communities and specifically developing forum theatre, for persons with AIDS.

Diamond, however, prefers to use the term 'Power Play', when introducing Theatre of the Oppressed to communities and schools, as he feels that the original (TO) terminology often causes unnecessary fear and tension among peoples, until they are actually participating in the workshops and have the time discuss, in detail, the origins of the drama practice. Throughout his workshops, Diamond emphasises concepts of 'oppression', encouraging the use of both adjective and verb as people realise, for themselves, the different levels of oppression, existing in their own lives and communities.

In referring to the Power Play and indeed to the Rainbow of Desire, one can find the synthesis of much of the liberation philosophy of both Freire's and Boal's pedagogies. We also have the opportunity to look to the practical work of many (TO) activists, who use dialogue and drama, in order to create environments from which individuals

might embark on their own process of conscientisation, and experience the demythicising their own personal realities.

‘The Power Play [or Theatre of the Oppressed] has...[taken] us away from the idea of making theatre *for* communities and making theatre *with* communities. The richest and most productive way to work with oppressed groups is to help them find their own voice; not to speak for them. When individuals don’t express themselves emotionally for long periods of time, they get sick; communities are the same. One way our communities can heal, is for all of us to take back our rights of healthy, collective expression.’ (2)

[Emphasis of Diamond]

In Britain, there have been movements on the part of dramatic and creative activists, for many years, which encourage otherwise oppressed individuals and communities to find their voice, in order to reestablish their rights of dialogue and healthy, collective expression.

This can be seen particularly in the work of educationalists like *Bob Searle* (1977), who worked with children in the East End of London, encouraging them to find their voices through creative writing and publishing their work which effectively cost him his job, in a school, not too far from those in which I presently teach. *Dorothy Heathcote* (1976), on the other hand, uses drama, as a powerful medium of learning in schools, hospitals, prisons, and a variety of other communities nationally and internationally. She, too, encourages people to regain their sense of dignity and empowerment, through her own dramatic and dialogical praxis.

‘The encounter with the role may be intense and absorbing for her pupils, but it will also be *objective* and *reflective*, since experience alone, without reflection, will not lead to learning...Her aim is to build on pupils’ past experience and give them a deeper knowledge, not just of themselves, but of what it is to be human; as well as an understanding of the society they live in; past, present and future.’ (3)

[My emphasis]

It becomes increasingly apparent to anyone who has read, or been associated with the work of these (and many other British educationalists/activists of the past 25 years), that a lot of creative and reflective praxis in Britain has been very effective in creating the opportunity for (at least) some of Britain’s oppressed to meet, identify and critically analyse their own realities, in working through their own process(es) of conscientisation. Although individualistic in approach, many educationalists have also adapted and incorporated successfully, many of the concepts of Freire and Boal, into their own teaching methods and style.

Tania, an HIV/AIDS educator, presently living and teaching in London (1994) describes for example, the positive (and often ‘hungry’) response of young people requiring informal education relating to ‘safer sex’:

‘They [the students] are generally 14-19 years old. They tend to want to know if you’re still in a relationship. Are you going to get sick? Are you going to die?...Because a lot of kids have been brought up on, you know, the scaremonger campaigns...The [British] government spent millions of pounds putting *a lot of* fear into people. But some of the kids are quite sensitive [pause]. They ask about my family, generally. Have they been supportive? [pause] And they want to know what hospitalisations are like...What illnesses I have today. And why do I do what I do now?
I say I do this [talk to them], because I don’t want it to happen to anybody else. And [that] I wouldn’t want anybody to go through the same experiences I’ve been through. It’s a lot of trauma for an adolescent..A lot of trauma for anybody. And I’ve had to grow up very quickly: emotionally, mentally and physically...’
[Tania’s emphasis]

When asked if she felt that people living with the virus and/or syndrome felt silenced, in any way, Tania replied:

Absolutely. I feel that really strongly, because there’s very much the sense that HIV is a kind of leprosy; that it’s contagious and not infectious.

Catrina: In 1994?

Tania: Oh yeah. I think the majority of people who are initially diagnosed, feel very silenced, you know. They feel a lot of shame.

Emerging from the personalised stigma so often associated with the virus and syndrome, is no easy task. And *finding a voice* in the epidemic, is made no easier by the renewed emphasis of the British government, to ‘control’ the development of HIV/AIDS education in this country’s schools.

Challenging the Culture of Silence Surrounding HIV/AIDS Education: A British Perspective

In theory, HIV education can be developed as part of the quasi-sex education curriculum of the British upper junior secondary schools. But in practice, the government has almost effectively stifled the most talented of teachers, by insisting adherence to *Section 28* of the Local Government Act (1988). This policy parallels, in many ways the US *Helms Amendment* (1987), which prohibits AIDS funding to projects ‘which promote homosexuality’, and extends itself to *exclude* the use of gay-positive material, in the teaching of HIV and AIDS. A climate of fear and *disease* has thus been compounded in this country’s schools, which serves only to further amplify the stigma and myths, already so wrongly associated with the virus and syndrome; while teachers continue to attempt to meet the

rigid requirements of an otherwise, already over-loaded teaching curriculum.

Tamsin Wilton, a lecturer in health and women's studies, at Bristol, England, puts it more succinctly:

‘Although the government was subsequently obliged to send out a circular to all schools, research reported in the University of Birmingham Cultural Studies Group, *Off Centre*, indicates that Section 28 has had a powerful negative effect on schools and colleges alike, to the detriment of activities as diverse as theatre in education performances, book buying in school libraries and equal opportunities work.’ (4)

Restrictive and homophobic government policy will not, however, dampen the dedicated and courageous efforts of those determined to educate (as a basic and fundamental human right), the young people of our communities, as to the facts and realities of HIV and AIDS.

When interviewed, Tania [previously cited] often spoke of the urgent need for educators to transcend the culture of silence surrounding HIV and AIDS.

When asked if she thought others, living with the virus and syndrome, would speak more openly about their experience of living with HIV and AIDS, given the opportunity, Tania replied:

‘It depends in what context. [pause] If they had a chance to be open about it in public, then it's not worth it, anyway. Because it's something very personal that you deal with...But as far as feeling silenced, in that HIV is not contagious...To be *unsilenced*...to make it acceptable...Then, I think they would [want to speak] because people want to be accepted with this illness as being normal. Not as being special, or different, or abnormal, you know.’

Catriana: What sort of things would have to happen, so that people...living with the virus, could feel they can break that silence?

Tania: Ah, more education. In the media. And in schools: that HIV is just another illness. And it *is* an illness. Not a penalty or death sentence...And people need to see that people can *live* with HIV. And there needs to be education at a young age, to promote safer sex....I want people to have a visual point of view, as well. A face and a personality, who has HIV. [Someone] who's living with it positively. And also for [young people] to see the negative effect of HIV too and how it affects so many people. It's like a domino effect around you. They need...to get more insight.

[Tania's emphasis]

The British National AIDS Trust Youth Initiative (1989-91)

Restrictive and homophobic government policy has not deterred the talented educators, working for organisations, such as the (British) National AIDS Trust. The educators, themselves, have succeeded in creating environments which encourage the youth of this country to provide us with their own (formally silenced) insight(s), and perspectives of the HIV/AIDS pandemic.

On National AIDS Day, 1989, the National AIDS Trust (NAT), organised a one-day forum at the Institute of Contemporary Arts (ICA), London; inviting a random sample of 60 young people from 8 schools and colleges in and around London to meet, discuss and reflect upon a whole range of HIV/AIDS related education materials. They were also encouraged to voice their own opinions, concerns and needs around HIV and AIDS.

The initial event was so successful, that in 1990, the National AIDS Trust approached the Health Education Authority (HEA), to develop the ICA event, so that it might be experienced by youth throughout the country.

The initial day's forum, had indicated that young people were not only *concerned* about the lack of HIV and AIDS education in their schools; but angry that they weren't being provided with the *opportunity* to speak openly about their *own* concerns, with those who might demysticise the mixed messages they were receiving, with regard to the virus and syndrome. The students spoke more specifically, of how their confusion was often compounded by the fact that, if discussed at all, HIV and AIDS were both 'talked around', rather than being 'tackled directly', in discussion.

In the early weeks of 1990, the National AIDS Trust developed a youth initiative, centred directly around the concerns and points of view, voiced by the young adults of the previous December. There was a need to discover if the findings were consistent with the needs and concerns of other young people, throughout England, and 'to gain a wider impression of the positive and negative factors, influencing the effective delivery of sex, HIV and AIDS education in schools and colleges'.(5)

The youth proposal, developed by NAT, became known as the *Living for Tomorrow* initiative and the ICA workshops were arranged to involve students from Bradford, Brighton, Bristol, Hereford, Liverpool and Newcastle, over the months of November 1990-March 1991.

All schools contacted, were advised that the workshops and evaluation sessions would be for young people only; that those attending, should do so, only on a voluntary basis and that the agenda of the day would be moulded to suit the specific needs and concerns of young people, attending.

This is not to say that the day, itself, was not formalised in any way. On the contrary. Each workshop was allocated its keynote speakers, and involved the use of video and specific education resources to be viewed (and assessed) by the students themselves, in relation to HIV and AIDS.⁷

The whole initiative (subtitled: *Making choices in difficult times*), centred around a type of action-reflection praxis, which encouraged the creation of environments in which young people could openly voice their concerns and demysticise issues of concern relating to HIV and AIDS.

Central to the workshop initiative was the use of drama. It was from here that the students began to feel confident enough to discuss their own concerns, confusion and anger, over the lack of HIV and AIDS education in their school and college environments.

Some of the following comments are indication enough, of the depth of concern the young people had been internalising (as virtual ‘cops-in-the-head’), for so long:

‘[You have] to talk about reality. You can’t censor life, you can only censor education. We’re going to find out anyway. So isn’t it much better to know the facts, than the myths?’

‘AIDS education [when taught] is being taught out of fear, not from the standpoint of self-respect.’

‘They’re happy enough to teach us history and geography. But they won’t teach us about something that could eventually kill us.’

It is not my intention here, to analyse in any great detail the tremendous influence and sense of empowerment experienced by those partaking in the workshops of that original National AIDS Trust initiative. Time and space will not allow for me to analyse work that was subsequently drawn up in report form, and is presently available from the National AIDS Trust, here in London.⁸

⁷ For a sample programme, please refer to the appendices.

⁸ The above publication is available from: National AIDS Trust, Room 1434, Euston Tower, 286 Euston Road, London NW1 3DN.

It is my intention however, to emphasise my original point that there is a desperate need among the young peoples of our schools and colleges to not only be informed about HIV and AIDS, but to be provided with the *opportunity* to discuss the issues that most concern them, in group situations and on a more interactive level. We are otherwise (through our own inaction), further encouraging the ‘generation’ of silence that feeds into the system of myths and stigma that has already been so inaccurately ‘associated’ with HIV and AIDS for so long.

Educating or Informing?

Young People Determining their own Health Education Praxis

It is important to emphasise, that there is a vital distinction to be made between *information* campaigns and *education* campaigns. The former usually takes the form of written materials, fed out to the public, en masse. The latter involves a more interpretative process, whereby the information is further clarified with and by the people choosing to receive it. (Tavanyer, 1992)

For a powerfully effective and culturally sensitive health education praxis to develop, it is essential that the students, themselves, should be an integral part of the developing pedagogy; assessing and evaluating the ‘education’ received, while constantly developing the process of learning to meet their specific concerns and emotional/cultural needs.

The National AIDS Trust *Living for Tomorrow* initiative chose, to use the results of its specific education campaign, to stimulate future initiatives at local and at regional levels, in an attempt to develop individual school policy reviews, potential guidelines and national recommendations for HIV and AIDS education policy and practice. But its primary objective was simply to begin working from the opinions and perspectives of young people, so that the development of future policy would be central to their specifically voiced concerns.

This sort of initiative is not unlike that of Freire’s, in the development of literacy education among his own peoples; or that of Boal’s, in the development of his own ‘spect-actor’ liberation praxis. From a Boalian perspective, we must all begin to see the urgent need, whether we be students, teachers and/or parents, to examine our own ‘internalised cops’ in relation to HIV and AIDS, if we are to deal appropriately and constructively with the culture of silence surrounding the epidemics. For the thread of commonality between Freire, Boal and the thousands of (often)

unrecognised HIV and AIDS educators is the need for each of us to find our own voice, in order to demythicise reality and recognise our own rainbow of desire.

In the time of an epidemic, however, there is often more than one power play in progress. And drama is often a means by which we can put action to the words we have lost to the silence of stigma, ignorance and fear so often associated with HIV and AIDS. It is becoming increasingly obvious from British and New York perspectives that our young people are beginning to find their voice in relation to all three epidemics and want to be heard. It is also time that we as parents, educators and policy makers began to listen to their combined and emerging voice:

‘However controversial it is, [HIV and AIDS education] must be made compulsory. It is not in our interests to keep information from us, that could save our lives.’ (7)

Notes:

1. Schutzman M (et al). *Playing Boal: Theatre, Therapy and Activism* New York: Routledge, 1994, p237.
2. Diamond D. Out of silence: headlines theatre and power plays. From: *Playing Boal* (op cit) New York: Routledge, 1994, p35.
3. Johnson L (et al). *Dorothy Heathcote: collective writings on education and drama*. Britain: Stanley Thornes Ltd, 1990, (5th ed) p12.
4. Wilton T. *Anti-body politic: AIDS and society*. Britain: New Clarion Press, 1992, p107.
5. National AIDS Trust Youth Initiative. *Living for Tommorrow*. London: Health Education Authority: 1991, p9.
6. National AIDS Trust Youth Initiative. *Living for Tommorrow*, p21.
7. National AIDS Trust Youth Initiative. *Living for Tommorrow*, p21.

'It *has* hit New Zealand, you know. Like, the figures *show*. I mean, New Zealand is getting just as bad as every other country in the world. [pause] I mean, it would be nice if they [the government] would take a look... I mean, I'm only 26 now. And I probably may live to the age of 30. It's more likely that I won't.'

Byron, 26, a New Zealander living in London, 1994.

Information or Education Campaigns? Developing School-Community Networks in the Face of the Third Epidemic

‘The scientists, policy-makers and media tycoons have the power to produce masks of otherness, which create discrimination against people with HIV and AIDS. They have the power to thwart prevention by allowing people to ignore the necessity of speaking about sexual practices, out of the false sense the HIV is somewhere else, in the bodies of others.’(1)

Before one can even begin to attempt to recommend possible policy-making strategies that will effectively educate our respective communities as to the issues and realities surrounding HIV and AIDS in the mid 1990s, it is essential to re-emphasise the multidimensional nature of the present epidemic, as it directly, or indirectly, affects our perceptions of it.

According to Dr Jonathan Mann, the founder of the World Health Organisation Global Programme on AIDS, there are (as previously cited), three global epidemics:

The first epidemic is identified the ‘silent’, ‘unrecognised’ development of AIDS through the 1950s to 1981.

The second epidemic is the one we are presently witnessing and have been experiencing since the 1980s in its visible form.

The third epidemic continues to be defined as the social epidemic which constantly perpetuates the prejudice and negative reactions of both governments and peoples, to the facts and realities of HIV and AIDS.

It is in examining this third epidemic that we will gain a small understanding of the repercussions of societal prejudice and its ever present potential to block the development of HIV and AIDS education praxis within our schools.

It has been more than apparent for the past decade that the gay communities throughout the world have, independently, laid the foundations of a powerful education praxis that examines and deals directly with both the

immediate and long-term issues of both the second and third epidemics. The same communities have ACTEDUP⁹ for a cure; fought for political change and policy development; lending much of their time, energy and resources to an often ignorant and bigoted society.

The repercussions of the third epidemic have been enormous, leaving many gay communities isolated, exhausted and unfinanced, while simultaneously, trying to cope with the grief and trauma of nursing and losing thousands of their close friends and loved ones.

Yet, from the earliest days of this epidemic, gay communities, throughout the world, have not only shared the resources of their action-reflection praxis, but have actively encouraged others to develop their own.

The task is made increasingly difficult when communities feel isolated and stigmatised by the media tycoons, who have so often succeeded in producing their own masks of 'otherness', which further serve to encourage the endless spiral of discrimination against people living with HIV and AIDS.

A small example of this can be found in just some of the many pages of derogatory terminology, I have gleaned from media articles and publications in recent years. Take, for instance, some of the following terms taken from so-called 'science' and 'human story' accounts:

⁹ ACT UP (AIDS Coalition to Unleash Power), formed largely by the gay community in New York City, 1988, was founded on a critical reflection praxis which encouraged direct public action in lobbying, protesting and pressurising the US government and Public Health Council to develop appropriate drug therapies for those living with the virus and syndrome.

ACT UP now protests the general inaction of the governments internationally, over many other HIV and AIDS related issues. Many other groups have since developed from ACT UP, including the Women's Caucus of the AIDS Coalition to Unleash Power, and ACT NOW (AIDS Coalition to Network, Organise and Win).

A Sample of Derrogatory Terminology used by the Media with Reference to the HIV/AIDS Epidemic

High risk group	Vectors of infection	Gay conspiracy
Reservoir of infection	Hidden danger	Safe population
Gay related explosion	AIDS suspects	Castration
Sexually promiscuous	Offenders	Sinfulness
Disease-free	Innocent victims	Wrong-doing
Sufferers	Carriers	Black Death
Noble epidemic	Queer bashing	Moral consequence
Killer disease	Deviants	Guilty
Contagion	Criminal	Sterilisation
Mainstream society	Alien	Scape goat
Reckrimination	Murderers	Stigma
Gay plague	Morality	Leper colonies
Junkie pneumonia	Diseased	Poetic justice
Public tolerance	Shamelessness	Secrecy
African AIDS	Hispanic AIDS	Prostitute's disease
Queer disease	Foreign	Plague
Wrath of God syndrome	Process of elimination	Rightful due
Contaminating	Full-blown AIDS	Extermination

Small wonder then, that when stigmatised groups *do* develop their own action-reflection praxis, they tend to withdraw from the largely white, homophobic and classist society which has oppressed them for so long, in order to strengthen their own boundaries, resources and steadily developing process of conscientisation.

This is often especially so for communities of colour; many of whom choose to also encourage the development of

pride, self-esteem and the fluency of their own first language, in dealing with the epidemic(s). It logically follows after all, that if a people is to confront the culture of silence surrounding AIDS, then the people can only do so with a voice.

The dominant cultures of our own respective countries have all too often been threatened by this: the fact that whole communities of oppressed peoples are now gathering to find their voice in the face of the third epidemic. There are also protests of 'exclusiveness' and oddly enough, racism, when these same groups (in confronting HIV and AIDS), choose to focus all their time, energy and resources upon educating their own peoples.

Yet the potential for developing a powerful education praxis in the face of HIV and AIDS has always been available to all. The problem for the largely white heterosexual population being that they have all too often been obsessed with issues of 'otherness'. i.e. "HIV and AIDS will not happen to me. It happens to *them*".

But since when did a virus have a race or gender?" (Patton, 1990) And how long will it take before whole societies come to terms with their own fear and denial, to realise that this virus has not so much to do with 'high-risk groups', as with high risk behaviours?

For too long, the fear and bigotry of whole societies has rendered them inert to the realities of all three epidemics. For the first ten years of the second epidemic, much of the white, heterosexual population have simply chosen to believe the propaganda of the third; too often shunning those who have tried to educate them otherwise. Alternatively they have, on discovering that a virus knows no sexual or cultural boundaries, bled the previously ostracised communities of their own limited and unsupported services; when all the while, they could and (still can), develop their own action-reflection praxis, appropriate to their own immediate needs.

The irony of the situation is that 15 years into the 'epidemic', the often dominant culture of the many countries, tends to *react*, rather than *act*, in the face of their own fears; often wasting still more valuable time accusing communities (which choose to critically reflect on their own developing praxis) of being separatist. Examples of this can be found throughout the world. They can certainly be found with regard to communities of colour in New York, London and Aotearoa/New Zealand.

But the reality is, we need to form many, many groups globally and within our own communities, in order to raise to consciousness, the many issues surrounding both the second and third epidemics. How else are we to make sure all our needs are met, in developing our health education praxis and in lobbying for effective education policy to protect them? We need to actively reflect upon the masks of 'otherness' cast upon us by the scientists, the politicians and the media tycoons. We need to find the strength to move out of our own personalised culture of silence. But, above all, we need to find our own culture, our language; our own sense of identification and self-esteem if we are, in the face of all three epidemics, to find a voice at all.

HIV/AIDS Health Education: An Aotearoa/New Zealand Perspective

Examples of powerfully developing HIV and AIDS education praxis can be found throughout Aotearoa/New Zealand among the gay community and among Maori and Polynesian peoples.

[The] Te Roopuu Tautoko Trust, established in 1986, provides full-time HIV and AIDS education for the Maori population of Aotearoa, focusing on the cultural perspectives; encouraging self-esteem and pride among its peoples, as part of its own critical-reflection praxis.

The Trust works from its national office in Wellington, but has regional offices in all four major cities of the country. From these four centres, a powerful process of HIV/AIDS education is networked out to Maori communities throughout Aotearoa, educating bilingually, but predominantly in the first language (Maori), to raise to consciousness the living culture of the people.

Culturally, this education praxis is centuries older than that of Freire, but many parallels can be made. We are not afterall, simply talking here, of education in theory. But education in praxis.

From the Maori perspective(s), HIV and AIDS education is continuously being developed by the people, for the people; as different issues surrounding the virus and syndrome are brought forward, through a powerful process of dialogue and action-reflection praxis.

A major function of [the] Te Roopuu Tautoko Trust is not only that of teaching Maori (and those working for the health services), the cultural perspectives of HIV/AIDS, STDs and sexual health; but that of creating a process of critical reflection praxis, that encourages conscientisation. The praxis itself, is developed by Maori, for Maori, as it moves from marae-based hui, into schools, factories, professions and out onto the streets.

Other examples of HIV and AIDS education that have developed among the Maori peoples of Aotearoa include the Awhina Trust and Te Puawai Tapu; the latter being a family planning organisation, run by Maori, working alongside the Department of Health in HIV and AIDS education, as it directly relates to youth.

The Polynesian communities of Aotearoa have also developed, for their own peoples, the Pacific Islands AIDS Trust. Established in 1988, this organisation focuses on bringing Pacific Island perspectives to HIV and AIDS education. The Trust works alongside programmes developed by the governments of their respective countries and has established its own Polynesian and cultural networks; creating their own action-reflection praxis among the Island communities of Aotearoa.

What I am attempting to illustrate here, is the fact that many communities of Aotearoa/New Zealand are attempting, and succeeding, in creating HIV and AIDS education praxis that directly encourages whole communities of peoples to find their voice in the face of both the second and third epidemics. In creating a meaningful education praxis, they have also developed their own culture of resistance, in order to confront the misinformation, all too often fed society by the government and the media.

The response of the New Zealand gay community to both epidemics began as early as 1983, with its own community of resistance rising in the form of the National Gay Rights Coalition. By the end of that year, the first HIV/AIDS education leaflet (*AIDS: Choices and Chances*), was produced. And by 1984, the AIDS Support Network was established, following the National Lesbian and Gay Conference. This was to function as a community-based HIV/AIDS support and education organisation.

In 1985, a trust board was established to fund the network that is now known as the New Zealand AIDS Foundation. This Foundation set up HIV/AIDS clinics and National AIDS information hotlines, and on finally receiving a

government grant, launched its first major public campaign in August of the same year. The Foundation now has offices in all major city centres, with networks extending out in an attempt to meet the needs of more isolated communities. Government health directories refer to the Foundation as providing 'professional' counselling and volunteer services for people with HIV and AIDS; which is of course, what they have been providing all along.

By 1986 several city-based groups of former injecting (IDU) users, had also begun their own peer-education praxis, educating each other about HIV/AIDS and providing outlets for needle exchange.

Peer-teaching continued (and continues) to rapidly develop among communities who, in trying to deal with the realities of the second epidemic, have had to cope with the two-edged sword of the third.

The New Zealand Prostitutes Collective, founded in 1988, is another example of a trust, developed in Aotearoa to encourage safer sex, outreach and dialogue among those too often ostricised, by those who just as often refuse to believe that HIV and AIDS is a reality for themselves at all.

Repercussions of the Third Epidemic: The Case Study of Byron, a New Zealander Living with AIDS in London, 1994

With all this said, there are sadly, no statistics to indicate the number of people who have chosen to leave Aotearoa in the past 15 years, simply because the repercussions and fear of AIDS made life intolerable and impossible for them to remain.

It is only fair to emphasise here, that the repercussions of the third epidemic can, of course, be experienced anywhere in the world. But the culture of silence, the fear, the stigma, imposed upon many New Zealanders diagnosed sero-positive, was often so intense (especially in the first years of the epidemic), that many felt they had no alternative but to leave their country, altogether.

In 1993, I began to meet several New Zealanders, presently living in London, who had, in testing HIV positive, decided to leave New Zealand during the 1980s as a direct consequence of their feeling stigmatised, isolated and/or ostricised by the larger community. Many of these people were unaware of the support services now available

(though not necessarily government funded), for those living with the virus and syndrome, back in Aotearoa. This was especially so, of those who had formally been (IDU) drug users and those from communities of colour.

Byron, 26, is one such New Zealander, who felt he had no option but to leave his country. On being refused admission to a maintenance methadone programme, in Auckland 1988, he and his doctor protested the action:

Byron: ...So I went to talk to my GP [doctor] And he just couldn't *believe* it. He was just like...He actually disbelieved me, at the time.

So, he rang the Minister of Health. And he told me to wait outside. And the Minister of Health, finally decided to ring him back eventually...And my GP asked the Minister of Health whether he could prescribe [methadone] for me, because he knew the dilemma I would be in, if I didn't get the medication.

And the Minister of Health said: "No. It's a restricted drug." You know: "You're not allowed to prescribe for him." He [my GP] said "Well, is there any way we can get him into a methadone clinic?" And they turned around and said "No."

[Interviewee's emphasis]

Byron goes on to describe how, in frustration, he confronted the Auckland authorities saying:

"What am I supposed to do? Go back onto the streets and catch AIDS?"

The reply had been: "yes."

Byron: So, anyway, in the end, we took it to the *Eyewitness News*. Eyewitness News took it on board. They interviewed the Minister of Health; the Methadone Clinic. And after the news story; after it came out as a report on the Eyewitness News, I ended up getting on the methadone programme the next day.

...Well anyway, I just thought: What about all these people, who are on the streets?...Do they go back out onto the streets to [get] AIDS? You know...end up back on the streets to die?...What *happens* to them? Do you know what I mean?...If I was turned away, you know, basically other people were being turned away, as well...Basically, the New Zealand government was saying to drug addicts "I'm sorry. We've got no treatment for you."

[Interviewee's emphasis]

Byron left New Zealand in 1988 and has been living in London ever since. He has found living with the virus a less isolating and less stigmatising experience, here in London; although he still seems to be unaware of peer-education and community support that has now been developed back in Aotearoa, and made available by people who, like himself, have struggled to confront the apathy and ignorance of the government. Or, perhaps he has simply, and understandably, lost the ability to trust a society that so obviously alienated him.

Byron: I've got loads of help, over here in London. And I mean this is...quite sad really, to think that a lot of New Zealanders really cannot go home and stay on a maintenance [programme]. I was *born* there. I'd like to go home and die there.

[Interviewee's emphasis]

In the same interview, Byron cites the example of a teenager he had recently seen, living on the streets with AIDS.

He emphasises that he is only one of many to find himself in the same predicament:

Byron:...What worries me...is when I *see*, like a 14 year old kid with AIDS...I mean, I'm talking about a 14 year old kid who will probably not live to the age of 16...on the streets, with AIDS...I'm not sure how he got it...I'm [pause] never really interested in *how* people ever get HIV. You know, things like that - their personal details - don't interest me. I think it's just the fact that someone, so young, is going to die so young, do you know what I mean?'

[Interviewee's emphasis]

In the time I have got to know Byron, he has also voiced how he feels it is essential that young people receive HIV/AIDS education and community services from an early age.

Byron: I think the people who are going to have sex, have to know...have to make sure [they're having safer sex] And if you *are* going to use drugs, make sure you use clean syringes and that.
...I mean, you *can't* stop people from having sex. I mean, if people are going to have sex [they're going to have sex] and they have to *know* how to take the precautions; to look after themselves. Because no one else is going to look after them.

[Interviewee's emphasis]

A Development of HIV/AIDS Education Policy and Praxis in the Schools of Aotearoa/New Zealand

The peoples of Aotearoa/New Zealand have been struggling for some time, to get effective HIV/AIDS education policy recognised and accepted, to protect the health education programmes they have already developed in their communities. This is particularly so of the formal education system (which I choose to define as a community within itself), where teachers wanting to educate about HIV and AIDS, often have to cope with the repercussions of the third epidemic and society's (often) general unwillingness to see it as a relevant subject to be taught in our primary and secondary schools.

Teachers often have another struggle on their hands, when it comes to convincing their colleagues, that HIV and AIDS education is essential for children of primary and secondary school age. Difficulties also arise when it comes to finding the time, training and resources to develop and maintain an effective HIV/AIDS education praxis, in this area.

In 1991, a survey was conducted nationally, simply to examine the current delivery of sexuality education programmes in the schools of Aotearoa/New Zealand. This was conducted by Forrest Chambers and reviewed at Forms I-VII levels.

A report was subsequently published, that indicated that many teachers felt that the school syllabus was already too 'over-crowded' to allow them the opportunity to incorporate HIV and AIDS education. Many who *did* wish to develop their health programmes, felt that they were limited by not having the appropriate training or resources; while others mentioned a 'fear' of the subject and the belief that school staff were restricted in developing more effective sexuality education programmes, by law.¹⁰

Not surprisingly, of the schools surveyed, none had managed at that stage, to develop school policy in relation to the subject area, at all. Many of those surveyed, had specifically expressed that they felt uncomfortable teaching health education in much detail, because of the Contraception and Sterilisation Act (which had originally prohibited teachers giving contraception information and advice to under 16-year-olds), but which was, in fact, repealed in 1990.

The final report, published by the Wellington Health Board, emphasised that although there are still legally binding requirements for consultation and approval procedures for sexuality education programmes in schools, these are only intended to be seen as legal *requirements*. Not as legal *restrictions*. It re-emphasised the need for appropriate training and resources for teachers; redefining (as it had already done in the introduction to the project), the essential difference between 'sex' education and 'sexuality' education.

From the onset, Chambers (1991) defines the term *sex education* as those technological/biological aspects of the subject; whereas, the term *sexuality education* refers more pertinently to the 'explor[ation] of feelings, attitudes, behaviours, pressures, risks, communication and health'. (2) These must certainly be explored by the students themselves if effective and culturally sensitive HIV/AIDS education praxis is to be developed within our schools.

Chambers describes the central aim of sexuality education as being that of :

¹⁰ See Chambers F. *Survey into current delivery of [NZ] sexuality programmes in schools, FMS 1-7*. New Zealand: Wellington Area Health Board, October 1991.

‘Improving the health and well-being of young people, by giving them the responsibility and ability to look after themselves.’(3)

The same report also emphasises that, for sexuality education to be effective, youth-needs in the area of sexuality and health, have to be established and regularly reassessed, via some form of youth consultation.

In (1992), Gillian Tasker began her own research into the effectiveness of a teacher development programme, in empowering secondary school teachers to develop and implement quality health /HIV-AIDS education in schools. Funded by the New Zealand Department of Health, this report focused even more specifically on HIV and AIDS education, via a cross-section study of schools in Aotearoa.¹¹

Although there may have been similar projects funded since, I will use this, as just one example of how teachers can become empowered to develop effective HIV/AIDS education programmes in their schools; while also creating confidence among school communities, to develop their own health education policy(ies).

In designing this project, Tasker, a senior lecturer in Health at Wellington College of Education, investigated over a nine month period, 8 clusters in the cities of Auckland and Wellington, involving 48 schools in all.

Tasker writes:

‘[All] schools involved, were required to have three teachers and a parent representative participating and to sign a contract agreeing to implement a classroom programme, focused on HIV/AIDS education [with] at least one [school] form-level in their school.’ (4)

The learning experiences developed in the schools, centred around the teachers addressing all of the following aims [listed on the following page], and gave teachers the choice of at which (or all) levels they were to be presented at. The requirement being that each of the aims would be addressed at least at one of the form-levels, and that all students at that form-level would be involved in the education process. Education resources were provided to assist the praxis.

The subsequent decision of the topics to be addressed at each form level, by the schools involved, are represented here, alongside their educative aims:

¹¹ See Tasker's report, by the same name, published by the Department of Health 1992/3.

Aims of HIV/AIDS education addressed at different form levels.

[Tasker Report]

Aims	Number of Schools at Each Form addressing each aim (N=11)					Total
	3	4	5	6	7	
1.To ensure all students are familiar with the facts about HIV/AIDS transmission	8	9	8	7	4	36
2. To ensure myths, prejudice and unnecessary fears are reduced	7	7	6	6	5	31
3. To increase compassion for those living with HIV/AIDS	6	7	5	6	5	29
4. To enable students to assess their own risk and make informed decisions which prevent them from transmission	6	8	7	7	3	31
5. To encourage the development of social and interpersonal skills necessary to carry out their own decisions preventing transmission	8	8	7	7	3	33
6. To encourage condom use for sexually active students	7	7	7	6	3	30
7. To affirm those students who choose to delay risk-taking sexual activity	8	8	7	7	4	34
8. To discourage risk-taking drug use	7	9	7	7	3	33
9. To foster a positive attitude to their own sexuality	7	8	7	7	5	34
Total number of times aims addressed at form level	64	75	61	60	35	

The objective of the project was to: ‘support young people towards a positive sense of their own sexuality, and to encourage them to develop knowledge, attitudes and skills which result in healthy sexual decisions’, by:

1. Empowering secondary school teachers to develop and implement quality Health/HIVAIDS education in their schools

2. Documenting the process so as to provide a model for further Health/HIV AIDS education in schools. (6)

Anonymous questionnaires were also provided,¹² to be completed at the end of all workshops. Taped interviews were conducted, during school visits. And records were kept (by the parent/teachers), of comments made during reflection meetings.

The project also encouraged parent and community involvement, with groups being asked in from the community, to assist on the education programmes. The parent-community, too, became involved; with both parents and teachers being asked to give their individual (and anonymous) reactions and responses to the praxis.

Those involved, were asked to reflect regularly on any/all issues of concern. These might include the time allocation, for each aim to be addressed; future training and resources required; with the examination of learning experiences, according to the level of student taught.

Tasker's project encouraged, almost in Freirian terms, the development of school health education as a critical action-reflection praxis, involving all parents, teachers and students in their own process of conscientisation. She further advocates:

'For health education to bring about effective learning for students, a shift [is needed] from a transmission of knowledge, teacher-directed approach, to a constructivist, student-centred approach.'

Tasker also emphasises that such an approach is:

'characterised by a range of learning activities which:

1. Actively engage students; enabling clarification of existing ideas, feelings, values, attitudes;
2. Encourag[es] the sharing [of ideas/experience] between individuals
3. Facilitat[es] their intergration with new learning experiences.' (7)

The results of this type of praxis speak for themselves:

The **students** involved in this project, found the education process very informative and relevant to their needs.

The **parents** enjoyed being involved and felt that they could provide a parents' perspective, while viewing ways health education could be taught. They were also impressed with the encouragement the project had given to the teachers and staff.

The **teachers** felt that the profile of health education had been enhanced in the school, while simultaneously providing them with various means to approach it.

¹² See appendices for an example of this questionnaire.

By the end of the project, if the schools involved had not already begun the process, *all* were now keen to write and present policy, to protect their developing HIV/AIDS health education praxis.

The only thing that was felt to be lacking (other than future funding and resources), was the much larger involvement of the more direct community, apart from those invited to speak at the health education sessions. Those invited had included the New Zealand AIDS Foundation, Homai Te Rongupa, public health nurses, local Maori, those involved with the AIDS Quilt Project, the alcohol and drug centre, sexual health centres and many others. But it would appear that even more of the community would become involved in time, given that this was initially just a nine-month project. Parents also wanted 'More involvement in school planning for both their own benefit and to relieve the pressure on staff'. (8) Parents wanted to be kept in contact with any forthcoming information and would willingly 'offer assistance, in any future training'. (9)

Overall, Tasker's schools project and investigation serve to re-emphasise that, not only are there both New Zealand parents and teachers willing to become more involved in developing HIV/AIDS education and policy development within their schools; but that there is also a pertinent need for all schools to be resourced and informed, if effective and culturally sensitive health education programmes are to be maintained.

Schools as Community: The Need to Involve Students Parents and Teachers in the Development of HIV/AIDS Education Policy and Praxis

Most of us, in educating and lobbying for government support in the area of funding for effective health education resources and training in our schools, are only too aware of the line of resistance presented us by our governments; who out of apathy and/or ignorance, so often deny us the essential funding we require.

The same governments can usually also rely on the media to fan-out to society, old prejudices relating to the third epidemic and sexuality education, should HIV/AIDS education programmes be proposed for our young people.

In order for schools to develop their own effective HIV/AIDS education praxis, they need to individually reflect on some of the issues surrounding both the second and third epidemics, so that they might begin a process of dialogue, in which students, teachers and parents, might all participate.

But firstly, they might want to examine how it is, they see their school, in relation to *society*.

Is their school, for example, regarded as:

1. Merely as an *institution* whose sole purpose is that of adhering to the 'banking concept' of education, (Freire, 1972); whereby, knowledge (as defined by the narrators) is fed to the students (the objects) who will, if 'successful', become the passive receptacles of the narration; fully able to regurgitate the contents, if and when it is required by society?

Or:

2. Is the school regarded as a *community*, (comprised of several or many communities), which chooses to be involved in problem-posing education (Freire, 1972); the type of praxis that examines knowledge through processes of dialogue; which allows students to move out of the role of passive receptors and into the more active role of 'spect-actors' [Boal, 1994], demythicising their own personal and social reality?

These initial points of reflection might seem fundamental, but are in need of clarification from the onset, if a good foundation of HIV and AIDS education praxis is to be established.

If a school, for example, sees itself in society, as belonging to the first category, then its HIV and AIDS education praxis might prove to be very limited, at least for the students concerned. I have already defined the distinct differences between HIV and AIDS *information* and *education* campaigns [Tavanyer, 1992] and these can be similarly paralleled with the differences between the successful teaching of *sex* and *sexuality* education (Chambers, 1991).

Presenting students with *information* about HIV/AIDS and sex education is all very well; but the facts presented by a 'narrator', don't necessarily mean that they have been received and assimilated effectively by the students. This is particularly so, if there is no time available for dialogue and active critical reflection.

This *lack* of critical reflection praxis can also be very damaging, in that it can cause unnecessary confusion and may

even serve to reinforce certain myths and stigma, relating to the culture of silence already surrounding issues relating to HIV and AIDS.

Patton, 1990, puts it more pertinently:

‘The silence surrounding saf[er] sex education for youth, (except for the “hard core, hard to reach” street youth, who we educate because we fear them), leaves many young people with the idea that only dangerous people need to know about saf[er] sex. My own experience suggests that “dangerous people” to these youth, are adults of approximately yuppie lifestyle.

Few people perceive themselves or their friends, to be dangerous, and believe they can proceed without any special knowledge or techniques. They [the youth] are smart enough to realise that something is wrong here, but unfortunately are too terrified, or simply don’t know how to get better information on their own.’ (10)

This is not to say that there are not many good teachers from (the proposed) second category, working hard in the more institutionalised schools of the first. But these teachers are often either ‘burned-out’ trying to convince the institutions at which they teach, of the fundamental necessity and authenticity of their HIV/AIDS reflection praxis. Or in time, they simply abandon the critical-reflection praxis altogether, out of isolation and lack of colleague support.

Let me re-emphasise that it is important for a school to see itself as community, as opposed to merely being an institution, in order for it to develop its expertise and strength in, not only the development of effective HIV/AIDS education praxis, but in the larger struggle for the development of effective education policy to maintain it. If teachers find themselves in the situation of being ostracised by a larger/unsympathetic institution, it is vital that they begin to establish their own networks with other teachers, in order to gain the support they require to develop and maintain their own education praxis.

Communities, throughout Aotearoa, have shown the vital need for such support-links and have shown all of society, the powerful and effective HIV/AIDS education praxis that can result from shared experience of the struggle and the subsequent sharing of resources and expertise.

The gay community has done it; communities of colour are achieving it and drug addicts (who have had to find their first voice through the silence of their own addiction), are now finding their second voice, to confront the culture of

silence, that still so often surrounds the epidemics. Is it not obvious that teachers should also be developing their own community of support and advice, if they are truly committed to educate effectively about HIV and AIDS?

Teachers are so often in the more 'privileged' position of having several communities within their institutions, from which they can also draw the needed expertise and shared experiences. But it will always require an action-reflection praxis, that will encourage those from their parent and student communities, to become equally participating parts of the education process. For a powerful and culturally sensitive HIV/AIDS education praxis to develop, teachers will also have to be willing to surrender some of their 'control' (so often associated with institutions of the 'banking concept' of education), in order to allow for the opportunity of community groups within schools, to educate one another.

Peer education (especially among students) could be one of the most effective and powerful resources available to teachers, who so often find themselves lacking in resources, not to mention, adequate curriculum timing. But firstly, teachers need to also recognise that peer education could be (and should be) an equally powerful and effective praxis for themselves.

Although I have already stated the need to 'draw-in' the larger community, to share their expertise as parents and visiting lecturers, I need to emphasise here, that teachers *also* need to be culturally sensitive and constantly aware of the demands that they may be making on communities who may already be exhausted from having to educate, over the past 15 years, a previously apathetic society. Teachers should also realise that if a community group refuses to participate in their education process, because it is fully involved in its own demanding praxis, then that is its prerogative. It is not separatist. Nor racist. But simply sensible, in a time when previously ostracised groups are doing all they can, to support and resource their own communit[ies] of people.

'Those of us most closely affected by the HIV epidemic are dizzy from trying to divide increasingly precious time between teaching about HIV, fighting political battles, and confronting the medical establishment, at the same time as we live through the fears and illnesses of our friends and ourselves.' (11)

Teachers must essentially gather; form networks and reflect upon the fact that they do have as much ability to mobilise in the face of the second and third epidemics, as anyone else. (Perhaps even more so, considering that many don't also have to cope with the personal stigma, so often and inaccurately associated with it.)

Once a constructive process of dialogue is begun, both parents and teachers can actively participate in creating their own school policy, around their own HIV/AIDS education praxis [as already demonstrated by Tasker, 1992]. Students, too, should be a part of this process, if both parents and teachers are to remain informed as to their own immediate needs, regarding HIV and AIDS education.

It would be valuable too, to have available, the response of New Zealand students, to such programmes. I am aware that a study is presently underway in Aotearoa, and it would be interesting to compare student concerns with those already surveyed here, in Britain. But more importantly, it would serve to act as an historic record of students themselves, finding their own voice as part of their own peer education praxis in relation to all three epidemics.

With such peer-oriented work underway within our schools, it would be only a matter of time, before whole school communities networked to find their own collective voice, and the confidence to continue developing their own effective health education praxis.

As schools become more 'user friendly', in terms of relating to the larger communities of society, possibilities could also open up to encourage those living with HIV and AIDS to come to speak in the schools, about their own personal experience of living with the virus/syndrome.¹³

This would serve to demythicise the 'reality' that the government, media and scientists have all too readily imposed upon society, in relation to HIV and AIDS. It would also provide another opportunity for all involved, to find their own voice; to express their concerns, their life-experience and hope for a more tolerant and educated society.

It is sad to reflect that there are so many New Zealanders who were not able to be part of such a school/community health education praxis in the early years of the epidemics. It is harsher still, to realise that they often felt so silenced and alienated from their own larger society, that they felt the need to leave their country altogether, in order to create for themselves, their own communities of meaning.

On the more positive side, many of these New Zealanders found their voice(s) long before most of the rest of us did. And if we are finally ready to hear them clearly enough, they still call to us from their own culture of resistance,

¹³ See the example of Tania, HIV/AIDS educator, in Chapter 2.

across the world:

'I was just a survivor. I survived...I was *very* lucky. That's just the way I am: a survivor.

...I don't know if it is anything like [what] it was like, when I was over there [in New Zealand]. It wasn't good. You know.

[pause]

...I've always admired New Zealand...being such an independent country. And New Zealand's always had such a good name. It would be nice...I would hope that New Zealand keeps with that. And, I think the worst thing that could happen to New Zealand, is for it to become conservative.

That's the worst thing that could happen to a country, like that....Because I think New Zealand is such a liberal, down-to-earth country. And I mean, I really do admire it for that, and so do a *lot* of other people around the world. And that's what it's *known* for, you know.

I mean, it had come a hell of a long way in the area of gay reform. And things like that. I mean New Zealand...Some of their policies and laws are very advanced...I think that's brilliant. And it's my ideal society. But there are still a lot of things that need to be looked at.'

Byron, 26 London, 1994. [His emphasis]

Notes:

1. Patton C. *Inventing AIDS*: Routledge; New York, 1990, p96.
2. Chambers F. Survey into the current delivery of NZ sexuality education programmes in schools, forms I-VII: Wellington Area Health Board, October 1991, p1.
3. Chambers F. Op cit p1.
4. Tasker G. *The effectiveness of a teacher development programme in empowering secondary school teachers to develop and implement quality health/HIV-AIDS education in their schools*. New Zealand AIDS Foundation, 1992-3
5. Tasker G. Op cit p5.
6. Op cit, p1
7. Op cit, p6
8. Op cit, p17
9. Op cit, p18
10. Patton C. Op cit, p102
11. Op cit, p107

'I was shy. I was scared of girls, till...much later. And when I went to school, upstate, I pulled out of the shyness. And I was brushing everybody. And then my attitude and actions started going around like that. [pause]

...That's what pisses me [off] about it. I knew what could happen. But I didn't think I could [get] it [HIV]. I thought I could spot the people that were 'high risk'. And I didn't know, that by doing that, I was creating risk.'

Richard (27)
New York 1993.

Critical-reflection Praxis and the Process of Conscientisation: Working Towards Effective and Culturally Sensitive HIV/AIDS Education and Policy Development within our Schools

'At the best of times, public information about sex is pitifully inadequate. Persistent government interference in education has denied generations of children access to adequate information about the world in which they grow up. In the name of 'protection', children are forcibly maintained in a state of ignorance, fear and vulgar prejudice about their own, and other people's sexuality.'(1)

In August 1993, I interviewed Richard, aged 27, of Stand Up Harlem, New York. Richard, having discovered his sero-positivity 3 weeks earlier, sat with me one evening, on the stoop of 145W 130th street, describing his initial shock and fear of the unexpected diagnosis. But Richard especially wanted to speak of education; of how he had been *informed* about HIV and AIDS (ie the *facts*) in school. But how he was never really presented with the opportunity to critically reflect upon the *issues* of prejudice, the myths, and the stigma of the third epidemic surrounding them.

Richard felt that a whole generation of young people had been (and still are), left in the precarious state of believing that they have been informed about HIV and AIDS (via the government, media and perhaps even in their own schools); while in reality they remain in a dangerous state of ignorance, as to their own prejudice and misconceptions, pertaining to the use of drugs; their own sexuality, and the fact that the pandemic concerns itself less with 'at risk groups' and more with 'at risk behaviours'.

Richard emphasises this point in an early interview:

'You know I think what the saddest part is...that they, [the young people] feel that they will never *get* to that point...We all think: "I'm not going to do this. I'm not going to do that -"
Well, everything I said I *wasn't* going to do, I did.'

[Richard's emphasis]

Several studies have already shown, in both America and Britain that most high school students often demonstrate a fairly extensive knowledge about HIV and AIDS. Some of this is initially gleaned from the media and much of it is analysed and reconstructed by the youth, themselves, as they create their own health education base(s) among their peers. (Patton, 1990)

There is certainly no denying that most young people are intelligent enough to discuss, in detail, issues of health and safety that could effect their whole lives. Yet, if their only source of information is that of the media, these so-called 'facts' of the second epidemic are seldom discussed effectively, in terms of their being distorted by the myths and prejudice of the third epidemic. This is often the case when young people are presented with the occasional line of facts, in their even more occasional school health education classes, *especially* if there is no opportunity for discussion and critical-reflection praxis provided.

Once again, young people are certainly intelligent and concerned enough to try again, among their peers, to disseminate and evaluate the information provided. But research has indicated, well enough, that young people are often left completely confused, if not bewildered by the process. Some, it is true, will become well informed purely by their own efforts. But the majority will either be left with a lot of unnecessary fears and unanswered questions (serving only to further mislead another generation, as to the realities of the epidemics). *Or*, they will simply withdraw out of a growing sense of powerlessness, into a state of apathy, when it is action that is urgently required.

Patton (1990) describes well, the tragic dilemma so many of our young people have to face, as a result of our own *inaction* in developing effective action-reflection HIV/AIDS education praxis within our schools:

'In fact, in most parts of the country, high-school and college students demonstrate fairly extensive knowledge about AIDS, most of which comes from the media; yet few practice saf[er] sex....Students who score high on AIDS facts tests, typically abstain from sex, until they get drunk enough to overcome their terror, at which point, they engage in unsafe sex which they later interpret with a mix of guilt, fatalism and a euphoric belief in their own good luck.' (2)

The tragic ineffectiveness of information campaigns, as opposed to education campaigns (or sex education, as opposed to sexuality education), is well researched and further emphasised by Warwick, Aggleton and Homans (1990), when similarly referring to students' self-acquired knowledge in relation to the epidemic(s) and their own often corresponding sense of fatalism.

'Several studies suggest that teenagers and young adults believe that other people acquire HIV infection or develop AIDS through a specific and known set of acts, while they perceive their *own* susceptibility to HIV and AIDS to be a matter of chance.' (3)

[Emphasis of Aggleton et al]

Young people themselves have often (when provided with an opportunity to find their voice), indicated their frustration at not being provided with a more effective HIV/AIDS education praxis within their schools. The work of the National AIDS Youth Trust, (previously cited) *Living for Tomorrow* initiative (1990), is just one indication of British children, voicing their concerns:

‘We need the facts about the transmission of [HIV/AIDS] up front, urgently, but we also need something to help bring the facts home.’

‘I think safe sex is so important, that it can’t be sacrificed because of parental wishes or because of the political devolution of power to the schools.’ (4)

Young people are also acutely aware that the education process will demand resources and funding of their already overworked teachers. And that their health education needs are not being prioritised by the governments of their respective countries:

‘Our teachers have so much on their plate, they haven’t got time to teach us about sex and how to protect yourself and that.’

‘[And] where is the money the government is spending? Who is benefiting? Because, we’re not.’ (5)

It becomes increasingly evident that the repercussions of the third epidemic extend not only to dehumanise those trying to live so positively with the virus/syndrome; as in the case of those who were diagnosed with no explanation and/or felt it a more humanising option to choose the anonymity and degradation of life on the streets (Charlene, Joe, Howard of New York; Chapter 1). But the repercussions of the third epidemic extend still further to those who finally find their voice and try to educate young people with their own survival stories (Tania, London, Chapter 2); to those who feel they need to leave the prejudice of their home country altogether (Byron, New Zealand/London; Chapter 3), when their deepest wish is to be able to return to their place of birth and die in peace.

Yet the repercussions of the third epidemic certainly do not end here. They also serve to silence those who want to educate about the epidemic; while our young people desperately try to educate themselves and are intelligent enough (and often angry enough), to occasionally find their voices in protesting the injustices of the third epidemic.

In reality, we are *all* affected by the third epidemic; whether we are living with the virus, educating as to the realities of the virus, or simply choosing to believe that it does not exist.

There is no denying that professionals in schools are affected by all three epidemics, right alongside the young people that they are (or are not), trying to educate with regard to HIV and AIDS.

This may 'appear' in the more subtle form of teachers never bothering to question their own prejudice and ignorance, relating to the epidemic[s]. Or, in other cases, results in teachers' dedicated, but often confused attempts to educate young people *effectively*, due to lack of funding, training and appropriate health education resources.

It is becoming a matter of increasing importance that teachers, too, be provided with the critical-reflection praxis, so obviously necessary for them to find their own voice; that they in turn may develop their own culture of resistance to the ignorance and apathy surrounding them. But inevitably, it is the young people who will suffer the direct consequences of our *inaction*; a reality that many of our young people have been angry about for some time. And a fact that they are finally rising up to give voice to.

In finding their voices, young adults are beginning to develop their own communities of resistance and meaning. Ironically enough, it is they (after all these years), who are directly facing the results of all three epidemics in a desperate attempt to educate each other; while protesting the ignorance and apathy of their older adult generation(s).

'We have adolescents here [in New York City] speaking about it [HIV/AIDS] And their group is called 'AIDS America is Dying Slowly'. And you know, there's a total of 15 groups...And they each have a name on their group. And they'll speak about it [their experience of HIV/AIDS] And...people who *don't* like to talk, are *talking*...The kids talk about it...telling [pause] us [adults]:

"Use condoms."

"Don't abuse us. Teach us."

"And don't abuse yourself. Teach yourself."

Lucy, 40 [Her emphasis]

Sadly, these 'kids' have only come to find their voice and develop their own health empowerment groups because society did not bother to take it upon themselves, to effectively educate them as to the risks of HIV and AIDS, in the first place.

It is a sad indictment upon our society, if our young people have to actually contract the virus, before their needs and voices are ever heard. These particular young people have finally gained access to resources and are determined to educate their own generation as to the realities of the epidemics; often educating the adult community in the process.

But the fact remains that, many of our young people continue to struggle through their own health education process in isolation and without the assistance that could (and should) be provided at an early age, in our primary and secondary schools.

Encouraging Student/Teacher Networks as a Continued Source of HIV/AIDS Education Support

It should be more than apparent now, that many communities (whether they be those of addiction, colour, gay and/or of youth), are all engaged in their own process of health education and are just as determined to become the executors of their own transformation.

In the New Zealand context, it has also been proven that young people want to be educated, as part of their schooling experience, as to the realities of HIV and AIDS; as do many of their teachers and parents.

On being surveyed, many New Zealand parents have already indicated that they not only approve of such health education being developed in the schools, but that they also want to become increasingly involved and active in the developing education praxis. (Tasker, 1993). This has been further confirmed by the *NZ Report on School's Project*, conducted by Forrest Chambers (1991-93).

There is to be found a very odd discrepancy then, occurring at government level, when one considers that adequate funding, training and education resources are still *not* being provided, for the primary and secondary schools of Aotearoa/New Zealand.

It would only seem obvious and an urgent matter of necessity, that whole communities of teachers, parents and students begin to mobilise, and network into communities of action, in order to collectively voice their concerns and lobby government into meeting their needs in this area.

As previously emphasised, teachers need not feel isolated, if the schools in which they teach are of the institutionalised 'banking concept of education' variety. Teachers, as much as any other community of people, have the expertise to network and become yet another powerful and articulate group of human beings; finding a voice for

their own needs and that of their students and parents. They too, have the ability to formulate HIV and AIDS education policy; not only at school level, but as a united and national organisation, reflecting the specific needs of their own respective communities of culture and colour.

It might also be appropriate and very powerful, for parents themselves, to form networks, finding their own voice to create their own respective national organisation; demanding that their own needs, and that of their children's be met in relation to HIV and AIDS education.

Young people too, are experienced enough (through their own informal processes of peer education), to network with other students nationally in order to form, for themselves, an organisation of student communities; to demand the education resources, training and financial assistance they need to become educated in the face of all three epidemics.

What I am proposing here, is that teacher, parents and students alike, gather themselves and the very few physical education resources they *do* presently possess, to begin their very own critical-reflection praxis; developing the talents they have always had, to bind together, find their voice and become the executors of their own transformation. In this way the government of New Zealand will be forced to listen to the voiced concerns of *all* communities within the schools; while those involved continue to grow in strength, having empowered each other through their own respective processes of dialogue and action-reflection praxis.

As teachers, students and parents continue to develop their respective health praxi in new educational settings, they will inevitably find one community educating another and another; each community subject to its own education process, but with the cycles of empowerment developing to include the experience and expertise of the wider community. In this way, whole populations of peoples can begin to involve each other as living resources; sharing their experience, strength and hope, without simultaneously exhausting (or detracting), from those communities needing to identify and work more specifically with their own targeted populations of primary need.

In essence, these respective processes of HIV and AIDS peer education could create a powerful stage of dialogue and action-reflection praxis that would, at the very least, create a sense of dis-ease among politicians who have for so long remained apathetic/adverse to the development of HIV and AIDS education in our schools. At the best such

developments would create a sense of uncertainty as to their political 'viability' should they not respond appropriately to the majority population (consisting now of so many communities), determined to develop their own HIV/AIDS education praxis in a school community context.

Initiating HIV/AIDS Health Education Praxis in the Classroom Environment

But what about the actual process of *beginning* such a praxis? How to *begin* with the content and application of such a pedagogy, in relation to HIV and AIDS in the classroom environment?

The answers to this, must always come from a continuous process of consultation, which encourages dialogue with the students involved. In this way, we as facilitators in the education process, can cooperatively evaluate with the students, what and how much they already know factually (and not-so factually), about HIV and AIDS; examining in the process, those aspects of concern, they wish to explore. This will serve as the initial and fundamental basis from which the educative process can begin; only to change, as determined by the needs and concerns expressed by students themselves.

Patton (1990) provides some fundamental assistance here, in guiding educators in the initial development of their own HIV/AIDS education praxis. She emphasises:

"Students need not only practical information and suggestions about the effects of the epidemic on social and political life, but they need critical skills to continue understanding the epidemic and its effects as medical information and policy trends change." (6)

Patton then advises educators in developing the content of their programmes to:

1. Avoid using the 'AIDS 101' format:

'Facts spawn facts, which become contradictory, leading people to be sceptical about any "answers" and reinforcing their existing prejudices and logics, which may not be useful tools for understanding AIDS.' (7)

2. Use a variety of media as a focus of discussion:

These resources can just as effectively be cuttings from local and national newspapers, AIDS factsheets, photocopied policy documents, life-stories, AIDS documentaries and even television 'soaps': Such resources can be utilised to begin discussion as to their relevance, their factual content (or lack of it) and/or their potential to prejudice/stigmatise the reality of those living with the virus/syndrome.

3. Use speakers to provide a variety of points of view:

Ask the students themselves who they would like to invite, in order to hear different perspectives of the HIV/AIDS epidemic(s)

4. Teach practical deconstruction:

This point is related to Patton's second point [cited] encouraging students to read regularly from a variety of sources.

But Patton defines the process of deconstruction more specifically as:

'students...evaluat[ing] the status of *their own* knowledge about AIDS, [while coming to] understand the implications of feigned ignorance. Critical *interventive* reading will impel students to read themselves *into* the AIDS episteme; will not allow them to fatally position themselves outside of, or in a place of exemption from the discourse of safe practices and social equity.' (8)

[Patton's emphasis]

The works of Freire (1972) and Dorothy Heathcote¹⁴, *Using Drama as a Medium for Learning* (1972-94), can also be consulted and developed to meet the needs of both teachers and students, as they arise. In fact drama is, in my opinion, one of the most powerful learning media to be used when integrated into the education process, as it actively involves the mind, body and emotions; providing an opportunity for collective expression, until students have gained the confidence to find their own voice in the critical-reflection praxis.

The work of Boal (1956-94) is also worth exploring, as previously cited in Chapter 2 of this thesis. Specifically relevant to HIV/AIDS education is his use of forum, image and invisible theatre practices; as is David Diamond's use of the 'power play' (1980-94).

From an Aotearoa/New Zealand perspective, there is much powerful work being developed in HIV/AIDS education, by the National AIDS Foundation; the Awhina Trust; Te Puawai Tapu; and the Pacific Island's AIDS Trust. The research and practice of Gillian Tasker (1993) is also available, as cited in Chapter 3 of this thesis; with the continued research of Forrest Chambers (1991-93) providing educators with some excellent initial teaching resources, (See his report on *Schools Project* 1991-93).

Student response to the British National AIDS Trust *Living for Tomorrow Initiative*, 1991 (also previously cited) is just one indication of how powerful the use of drama can be, as a medium for learning about HIV/AIDS:

'Drama is really helpful. You react emotionally, which helps you to identify with the issues.'

'People have sex before they are 16. You can't ignore it. You may not like to think they do. But they do. And they are at risk.'

'Videos don't really bring the point home [when used on their own]. If they're used well, then I suppose

¹⁴ Videos of Heathcote's work are available in both Britain and New Zealand, as the educator conducted a series of workshops in Aotearoa, in recent years.

they are quite good. But not anything like discussions, or drama.' (9)

In the same report, students also emphasised the value of learning about the epidemic(s) from those with whom they most identify and the significance of being given the opportunity to assimilate/reflect upon more personalised realities, in a peer-oriented process of dialogue:

'Meeting and talking to people with the virus helped me to realise that this [HIV/AIDS] is real. It's now, and it concerns me. It totally changed the way I think about it.' (10)

Encouraging the Use of Peer Education to Determine the Long-Term Effectiveness of Our HIV/AIDS Education Programmes

The value of peer education is often under-estimated or overlooked, in the development of HIV/AIDS education praxis within our schools. For those finding it difficult to find the initial funding and resources to support their own health education praxis, it would seem the obvious place to start; given that peer conformity, identification and bonding are most apparent in the teenage years and that there are several studies which repeatedly indicate that 'there is a greater subsequent exchange of information and active learning when peers are involved.' (Peer, 1987, De Motta, 1994)

De Motta (1994) also emphasises that we all too often approach HIV/AIDS education from the perspective that our young people are of the 'non-adult' status; that they become the passive recipients of our own information-oriented messages. She reconfirms the need for educators to develop their HIV/AIDS education praxis from the voiced needs and concerns of the students themselves (as opposed to developing ours from priori assumptions) and to encourage the development of peer education processes which involve students in a praxis, which essentially includes educators, with whom they can identify and respect.

De Motta defines peer education as:

'Describing a multitude of possible strategies [which include] youth educators working with groups of contemporaries in workshops and drama and as individuals counsellors. It can be interactive and participatory or "telling it like it is".

For some, peer education entails working from adult-defined priorities and formats; for others it entails addressing the needs of young people themselves.' (11)

De Motta confirms again, the need for HIV/AIDS intervention to be developed closely with the [school] communities involved, taking account of the social, political and cultural histories of those particular communities and providing all, with the opportunity to regularly and critically reflect upon their own developing health education praxis.

In a New Zealand context, Geraldine McDonald has recently evaluated the NZ *Combined Colleges of Education, HIV/AIDS-Sexuality Education Teacher Development Programme*, 1994, which indicates that there is a developing sense of confidence among teachers and parents alike involved in their respective HIV/AIDS education praxis.

In her second evaluation, the effects of classroom programmes on students are explored and some of the needs of Maori peoples addressed, further indicating the very positive outcomes of HIV/AIDS education praxis in the schools of Aotearoa. It was possibly beyond the scope of this project to include the voices and comments of the students themselves, but this would serve as a valuable source of information for future research, especially if the research itself, were funded to examine the specific value and developments of peer education in other curriculum areas relating to HIV and AIDS education. There has been some excellent education praxis developing in some of the schools of Christchurch, New Zealand, for example, that I only came across as a researcher in the field of peace education, 1989-90. Some of the peer education praxis in these schools could be further investigated as to their potential for providing communities of students, teachers and parents with an added resource and dimension to their own developing HIV/AIDS education praxis.

In her second evaluation, McDonald also reports the continued development of parent/teacher team participation, in which peer-oriented processes are obviously being successfully used among both parent and teachers, to further the long-term effectiveness of HIV/AIDS education in the schools of Aotearoa. There is also indication of the successful development of bi-cultural workshops, the use of hui and the creation of a bilingual resource package on HIV/AIDS sexuality education to be used by teachers, parents and students, within the schools of Aotearoa. McDonald further confirms the fact that both parents and teachers are becoming increasingly involved in the development of HIV/AIDS education policy within New Zealand schools and that a broad and integrated Maori policy on HIV/AIDS sexuality education is to be developed for Maori, by Maori peoples; reflecting the needs of Maori from both language and cultural perspectives.

For all its excellent and thorough investigation, there is one point of concern which I must raise here, in relation to the McDonald Report. In evaluating the value of bicultural workshops, McDonald does make the following remark:

‘The HIV/AIDS teacher development workshops are about Health and there would be no justification for turning them into anti-racism workshops.’ (12)

On this point, I cannot agree. Racism is as interconnected with issues concerning all three epidemics, as are classicism and homophobia. If critical-reflection involves the need to voice, even angrily, interrelated issues of racism [whether it be on the part of students, teachers or parents], then it is vital that they be expressed as part of the continued process of conscientisation. Health *is* political and the emergence of the HIV/AIDS epidemics cannot be seen in isolation from the issues that have been left unresolved in the many years preceeding the epidemics.

McDonald writes:

‘A legitimate goal, however, might be to explain the Maori viewpoint and the effect of the status of Maori in Aotearoa on the sexuality and sexual risk of Maori youth.’ (13)

But who has defined this ‘legitimate goal’? The health/education authority? Or the Maori peoples of Aotearoa, themselves? Are we talking, here of information campaigns, or of education campaigns? And are we educating from the perspective of the humanist, or the humanitarian, when Maori peoples have their own specific aims, needs and concerns to address in relation to all three epidemics.

I do agree with McDonald that the emphasis of health education should be on ‘explanation not blame’. (14) Although I would further suggest that ‘explanation’ is only one aspect of a successfully developing HIV/AIDS pedagogy. Finding a voice in the epidemics is vital for all those involved in the praxis, if we are to successfully address the prejudice, myths and stigma surrounding HIV and AIDS. The process of conscientisation is not always a comfortable one, but will lead to the long-term effectiveness and applicability of our health education praxis. If Maori peoples feel marginalised, as they have every right to, given the history of Aotearoa, then it is essential for them to voice their concerns, as much as do the Irish peoples (Positively Irish Action against AIDS), living with the virus in Britain, or as do Black and Hispanic peoples of Harlem, New York.

It may seem initially unfair to refer to this one paragraph, in an otherwise excellent report on the successful progress of teacher development and HIV/AIDS sexuality education praxis, in Aotearoa/New Zealand. Yet it is extremely

relevant, when considering the need for the development of sensitive and effective peer education praxis, if we are all to come to terms with the many repercussions of not one, but three global epidemics.

Peer education occurs at many levels, encouraging the collective action of all of us to find our voice and express our concerns in relation to all of the HIV/AIDS epidemics. Issues of 'blame' can be addressed, as the process of action-reflection praxis develops; as will issues of apathy, anger and grief. The process of conscientisation is often an emotive and painful one. But will inevitably lead us into being the subject of our own transformation, as we begin to meet our own prejudice and de-mythicise the reality that has kept us silenced for so long.

With a World Health Organisation estimate of half a million lives lost to AIDS, and a further 13 million more infected with the virus, it is important for all of us to maximise the use of our shared language, experience and cultural/political concerns.

'Peer education will have different messages and different targets in different communities. The basic philosophy of peer education is that, given the correct environment and support, everyone has something to offer.' (Haffner 1988/De Motta, 1994) (15)

Perhaps the developing peer education of our youth has something to teach us all, as we watch our young people (in a London/New York context), challenge the apathy, fear and prejudice that have, for so long, kept us submerged in our own culture of silence, in relation to all three epidemics.

De Motta (1994) cites young people emerging from their own HIV/AIDS education praxis, as they move out into the community to design and develop their own health education messages and resources; using the languages and images of their own personal realit[ies] to educate youth of a similar age and experience. She describes young people as gaining a new sense of confidence, as they begin to examine the reality that the government and the media are *not* all-powerful; that they as individuals, *do* have a voice (and the ability) to become an important part of their own health education praxis, while contraposing the pessimism that has so often kept them fearful, to the point of apathy, in relation to their own health needs and concerns.

Young people in both London and New York are now creating their own HIV/AIDS health education workshops; debating many of the political issues that surround all three epidemics, while working closely with schools as an

important part of the health education and policy-making process. Young people are using drama to challenge their own 'internalised cops' (Boal, 1994); while moving out further into the community as operators of their own telephone helplines, as peer counsellors and as community educators.

Peer education has long since proved to be an essential and powerful tool in the successful development of HIV/AIDS health education among the formally 'marginalised' gay communities and those of addiction and colour. Peer education does, however, require facilitators. All of us have the ability to become involved in the process, whether we be parents, teachers and/or students of the praxis. And all of us have the opportunity of gaining far more from the process than we could have ever possibly hoped to give.

It is time that we all began to see our own place in the epidemics; participating in the development of our own critical-reflection praxis. We need to provide our future generation of young people with the opportunity to find their voice and become involved in their own processe[s] of conscientisation, while encouraging them to participate fully in their own HIV and AIDS education praxis.

It is time, too, that we encouraged our young people to become increasingly involved in policy making decisions that will determine the long-term effectiveness of a culturally sensitive and powerfully developing pedagogy; so that they, in turn, might walk into the future, not only knowledgeable as to their own health and personal/political realities, but with a renewed sense of confidence, empowerment and hope.

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'We have to take some of the positive things we have done for ourselves and say: "We can change."

We need to get out of [having] to know it *all* ourselves. So that it's not so much of a burden...So [we] can go out and educate those people who [supposedly] don't have HIV, to prevent them from getting it. And *even* if they do get [the virus]...well, you know: here's a little support group.

This way, the people out there, can be more educated, you know. Whether it's in England, France, Germany, New Zealand; wherever.'

Howard (26)
New York, 1993.

Conclusions

‘There is...evidence, that community-oriented approaches to AIDS education can be very successful in meeting a wide range of health related needs...There is also growing recognition that if AIDS education is to have long-term effectiveness, health educational interventions must be linked to changes in policy and legislation.’(1)

In writing this thesis, I endeavoured to use some of the voices of those I have met, living with the virus and educating so positively as to the realities of HIV/AIDS, London-New York, 1993-94.

I have deliberately moved away from the more conventional approach of thesis writing, in order to set the voices of the interviewees themselves, as the focal point of the project; having them describe their own personal reality of the epidemics and the experience by which they first came out of isolation, to find their voice.

In so doing, these individuals have begun a process of dialogue with the larger world, as to their developing education praxis and the need for all of us to develop our own cultures of meaning and resistance, in dealing with the issues surrounding all the realities of the present pandemic.

It has been essential to define this pandemic as consisting of not one, but three base epidemics, as defined by Dr Jonathan Mann, founder of the World Health Organisation Global Programme on AIDS. Without this very basic understanding of the pandemic many of us will, through fear, ignorance, apathy or fear, continue to distance ourselves from the stigma, prejudice and mythology surrounding all three epidemics; when, in reality, we are all affected by the pandemic, whether we are living with the virus, affected by the virus, or simply choosing to believe that it does not exist.

Alternatively, some of us might become so ‘socially conscious’ of the first two epidemics, that we develop specific HIV/AIDS education ‘programmes,’ without realising that we may, in reality, be adding to the repercussions of the third. We can do this in a number of ways, as a matter of ignorance, rather than intent, by failing to address our own preconceived notions, not only of the virus and syndrome, but of the many issues surrounding sexuality, racism and addiction. It is essential therefore, for all of us, as educationalists, to engage ourselves in our own critical-reflection praxis; with some of the points of reflection (among others) being that of :

1. Examining our motives - Are we, for example, acting from the standpoint of the humanitarian; or the humanist?
2. Examining our own issues around racism, classism, addiction and homophobia.
Issues of ageism might also be pertinent here, with regard to our young people and their potential to also educate us as part of the peer-education process.
3. Examining the 'facts' presented us by the government and media in relation to the part they may have played in reinforcing the myths and prejudice surrounding HIV and AIDS.
4. Consulting the educationalists who have been dealing with the virus and syndrome on a personal and professional level, for the past fifteen years; while being aware that their energy and resources are often over-prescribed.
5. Accepting that some communities, specifically targeting their own populations, ie gay, those of colour and addiction, may often need to decline requests of physical assistance and resources (after having provided them to all for the past decade), purely for the fact that they are overworked, exhausted and needing the time and space to further target their own population, while consolidating their own action-reflection praxis.
6. Allowing the HIV /AIDS education praxis to develop from the voiced concerns and expectations of the targeted population, itself, eg. those of primary school age, college and tertiary communities; the educationalist consistently reassessing her/his role as that of facilitator, while the 'targeted' group enters into dialogue and becomes the subject of its own transformation and process of conscientisation.

This may, at first, seem a tall order for the educationalist; but, in reality, the most effective HIV/AIDS education campaigns (as opposed to information campaigns), have resulted from the incorporation of such points into the very foundations of their now developing praxis. Examples of this can be found among the communities of London, New York and the gay, Maori and Polynesian communities of Aotearoa/New Zealand. An educationalist who chooses to guide groups of youth, for example, into a process of his or her own conscientisation, must be willing to become consistently involved in their own. Otherwise s/he may only be serving the short-term interests of a few, while inadvertently creating a false sense of security among youth, who might continue to believe that HIV/AIDS relates to

'high risk groups' as opposed to their own high risk behaviours. Educationalists also have the responsibility of helping to demythicise the realities of all three epidemics, rather than add further, to the repercussions of the third.

In writing this thesis, I have attempted to introduce some of the education theory pertaining to Freire and Boal, including samples of critical-reflection praxis as espoused by those living in the communities of Stand Up Harlem, New York, and of those involved in educating as to the realities of the HIV/AIDS on an individual (and often poorly funded basis) in the schools of London. I have also included the praxis of those involved in the National AIDS Trust Youth Initiative, London 1991, believing that it gives voice to the frustration of young people (as to their not being previously educated adequately about the virus and syndrome); while illustrating their enthusiasm to become more involved in the education praxis, and their keen level of perception as to the difficulties facing their own teachers, in terms of training, timing and resources needed to educate them effectively.

The work of New Zealanders Forrest Chambers (1991-93), Gillian Tasker (1992-93), and Geraldine McDonald (1994), have also served to illustrate some of the excellent HIV/AIDS praxis being developed in the schools of Aotearoa; while simultaneously confirming the fact that many teachers, parents and students of New Zealand not only approve of HIV/AIDS education being taught in their schools; but urgently require government funding, training and resources to support their praxis.

The later work of both Chambers and McDonald also determine that school policy development is underway in Aotearoa. Parent and teacher response as to their willingness to become more involved in the various HIV/AIDS education praxis, is well documented. It is my hope that the voices of the students themselves, will soon too be documented, so that whole networks of school communities may be formed, in an effort to lobby government at national level, for legislation that will protect the long-term effectiveness of such programmes.

My original aim in writing this thesis, was to document some of the voices of those specifically living with the virus/syndrome; who had found their voice through their own critical action-reflection praxis and who have decided to educate others as to the prejudice, mythology and stigma they have personally experienced, in relation to the epidemics. This project, however, will be a long-term one; the people of Stand Up Harlem, being keen to encourage other communities in London and New Zealand; to hear their voice as they develop their communities of meaning

and resistance, and begin to reciprocate the realities of their own.

more susceptible to the real risks of the 'epidemic': the arrogance and ignorance which only serve to perpetuate the social repercussions of apathy, fear and prejudice for those living with HIV and AIDS.

Throughout this very initial investigation, the use of grounded theory methodology (Glaser and Strauss), has brought to light many interrelated issues surrounding HIV and AIDS health education, and the need for all of us to find our voice in the face of all three epidemics. This thesis was divided into four chapter/modules, with the deliberate intention of allowing the issues and the voices of those interviewed, to emerge and generate theory that might well act as small foundation 'building blocks', for future research. Many of these issues raised, require immediate and indepth consideration:

1. The examination of student/youth response to the HIV/AIDS epidemics, along with their specific concerns in a New Zealand context is, for example, imperative, if we are to develop effective and culturally sensitive health education praxis within the schools of Aotearoa.
2. The documentation and presentation of successful HIV/AIDS education praxis is needed as it occurs among:
 - (a) communities of colour
 - (b) communities of addiction
 - (c) communities of parents, students and teachers.

This is essential, not only as a means of educating as to the realities of all three epidemics, but as a source of strength and inspiration for those who continue to struggle with the development of their own health education praxis and policy development, both nationally and internationally.

3. The continued evaluation of various peer education praxis and the collation of HIV/AIDS education resources in cultural contexts is also vital; as are listings of developing health education networks within our schools and the presentation of student/parent/teacher initiatives in lobbying and developing health education policy that will determine the long-term effectiveness of our HIV/AIDS health education praxis.

It is my own intention to continue recording the experience, strength and hope of people presently living with the virus, as they emerge from their former culture of silence to develop their own critical-reflection praxis, and which

deals specifically with the realities of all three epidemics.

My intention is to develop both an historic record of their personal experience, as it relates to living in London, New York and Aotearoa/New Zealand contexts. And a means by which the voices themselves, can give hope and strength internationally, to those who have suffered for so long, the repercussions of the third and present epidemic.

It is also my intention to record the realities of those New Zealanders presently living in London with the virus and syndrome, hoping to give voice to their own life experience and the possibility that we may together create a powerful education resource to encourage dialogue and reflection in the primary and secondary schools of Aotearoa.

It is perhaps fitting that I conclude this thesis with the words of Byron:

'I mean, if I could go back home...Like...If there's support there. And I could live there...That would be the most ideal society; the *most ideal* world. And not just for me to live in. But everybody. You know what I mean? It would be absolutely amazing.'

Byron, 26, a New Zealander living in London, (1994)

[His emphasis]

It is time that we all began to see our own place in the present pandemic; educate ourselves as to the realities of both HIV and AIDS. And participate in our own renewed process of conscientisation.

As educationalists, we need to provide opportunities for dialogue and critical-reflection praxis among our young people; encouraging them to become an active part of the health education and policy development process, while coming to terms with the prejudice, myths and stigma so often associated with the third epidemic.

It is only in finding our voices and emerging from the culture of silence that has, for so long, surrounded all three epidemics that we will begin to develop policy that will determine the long-term effectiveness of culturally sensitive and powerful HIV/AIDS education praxis, and create for our present and future generations, a more just and humane society.

Notes:

1. Aggleton, Peter, et al. *Social aspects of AIDS*. Falmer Press, Britain, 1988, p167.

"Nau te rourou, naku to rourou, ka ora ai te iwi"

"With your basket and my basket, we will ensure that the people live"

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APPENDICES (i)

Glossary of Terms

Literature Review

GLOSSARY

AIDS	Acquired Immunodeficiency Syndrome. Acquired means that it is caught as opposed to being inherited. Immunodeficiency describes the state when the body's immune system is dysfunctional or depleted, so that it is unable to defend itself against the development of certain conditions, particularly infections. Syndrome the particular variable pattern of symptoms and signs indicating the presence of a condition or disease.
Antibody	protein made by the body's immune defence system to fight off infection. Antibodies are made after the body reacts to the infection or virus. If HIV antibodies are in the blood that means the body has been exposed to the virus, and the body has responded by producing the antibodies.
Antibody tests	the test most commonly used for screening blood for HIV is called ELISA (enzyme linked immunosorbent assay). The test used by reference laboratories to confirm the ELISA is called the Western Blot.
Antigen	protein part of an infecting organism that identifies it and acts as a signal for the body to produce antibodies.
B-lymphocytes	a group of white blood cells that produce antibodies in response to contact with antigen.
Candidiasis	a fungal infection of the lining of the mouth, gullet, and gut; occasionally on ordinary skin. Other names are thrush, candida, monilia, yeast infection.
DNA	deoxyribonucleic acid, the carrier of genetic information for all organisms except certain viruses.
Haemophilia	an inherited disorder in which blood cannot clot properly. People with haemophilia can lead relatively normal lives if they receive regular blood products such as factor VIII.
'Helper' cells	are a type of T-lymphocyte which co-ordinate the immune response, stimulate other T-cells and assist the B-lymphocytes in producing antibodies.
Herpes viruses	there are six major types in humans: - herpes simplex virus Type 1 (HSV-1), cold sores - Type 2 (HSV-2), sores on the genitals or anus - varicella zoster virus (VZV), shingles - Cytomegalovirus (CMV), - Epstein-barr virus (EBV), glandular fever - human herpes 6
HIV	human immunodeficiency virus: the correct name for the virus that causes AIDS. Earlier names included LAV and HTLV-III.
HIV infection	the virus has entered a person's body and antibodies to the human immunodeficiency virus are present in the blood.
Immune system	the body's defence mechanism which fights off infections and certain diseases.
Immunology tests	blood tests which indicate the state of the immune system, eg the number of CD4+ lymphocytes.
Incubation period	the time that passes between the agent causing infection entering the body, and the appearance of signs or symptoms of disease.
Intravenous	into a vein.

Kaposi's sarcoma	a rare type of vacular tumour usually on the skin but also affecting mucous membranes or internal organs.
Latency	a period when the virus is still in the body, but is dormant or at rest, causing no signs of illness.
Lymph nodes	gland structures distributed throughout the body in which lymphocytes are concentrated.
Lymphocytes	white blood cells particularly concerned with defence against viral, fungal, parasitic infection, and tumours.
Lymphadenopathy	enlargement of lymph nodes, most noticeably in the armpits, neck or groin.
Macrophages	cells that interact with B and T-cells as part of the immune response. They are long-lived scavengers that cruise through the body ingesting micro-organisms or other cells and foreign particles or debris. They signal other cells in the immune 'orchestra' to play their part.
Opportunistic infections	infections which occur when the immune system is not working well. Normally the healthy immune system keeps them in check.
Parentally	by injection or through the vein.
Pneumocystis carinii pneumonia (PCP)	a rare form of pneumonia. It usually does not cause a recognised infection in a person with an intact immune system. It is the most common fatal infection for people with HIV and the most common AIDS-defining infection.
Prophylaxis	preventive treatment against disease.
Remission	when the symptoms, signs or severity of a disease lessen or disappear over a period of time. The disease may still be present.
Retrovirus	HIV is a retrovirus. Once it has invaded a T helper cell, it copies itself into the genetic code of the T-cell. In effect this transforms the T-cell into a factory which makes new viruses and releases them into the bloodstream.
RNA	ribonucleic acid - found in all living cells. Messenger RNA transforms information from DNA to the protein-forming system of the cell.
Sentinel testing	the collection of information, through sites accessing individuals exhibiting risk behaviours, regarding the distribution and determinants of HIV infection. This is pertinent to the design, implementation or monitoring of prevention and central programmes and activities.
Seroconversion	the appearance of specific antibodies in a person as a result of an infection or immunisation.
Seropositive	blood which contains a particular antibody. Someone who is seropositive for HIV has HIV antibodies in their blood. The opposite is seronegative.
Sexually transmitted disease (STD)	diseases such as gonorrhoea, chlamydia, syphilis and HIV infection which can be passed on during sexual activity.
Suppressor	also known as T-lymphocytes, these damp down immune response when it is no longer needed. These cells are often increased during HIV infection.
T-lymphocytes	see helper and suppressor cells. There are three kinds of T-lymphocytes (T-cells): helpers, suppressors and killers. In HIV the normal ratio of helper to suppressor is often reversed.
Virus	a micro-organism which cannot independently reproduce itself. A virus infects a living cell and uses that cell's processes for reproduction.

Review of Literature

For a deeper understanding of the research and methodology used in this thesis, I would recommend the work of Glaser and Strauss, *The Discovery of Grounded Theory*, 1968. This is a particularly good introduction to the use of grounded theory in social research and is specifically relevant for those wanting to gain a basic understanding of the philosophy, concepts and methods that can be successfully utilised in generating qualitative data and theory, in their own specific areas of field research.

The writings of Paulo Freire are also invaluable for those interested in the field of community education and for the humanising, self-empowering philosophy, and concepts it can offer the communities of students, parents and teachers in our primary, secondary and tertiary systems of education. I would specifically recommend Freire's *Pedagogy of the Oppressed*, 1972, followed by his work *Cultural Action for Freedom*, 1974, as a means of reviewing Freire's own developing praxis and ways in which his concepts of problem-posing education and conscientisation can be seen as increasingly relevant and applicable in a so-called 'first world' context.

For those unfamiliar with the facts, definitions and medical conditions relating to HIV and AIDS, Tavanyar's work, included in The Terrence Higgins Trust *HIV/AIDS Handbook*, 1992, is an excellent resource. She not only discusses the facts and fiction pertaining to the transmission of HIV, but provides information on safer sex, the HIV antibody test and constructive advice on matters related to living with HIV/AIDS and/or caring for those with the virus and syndrome. Tavanyar also provides a very good historic analysis of the development of HIV in Britain, looking specifically at issues of discrimination; of drugs trials, HIV/AIDS education dilemmas and the struggle for human rights.

Essential reading, for all involved in HIV/AIDS education research, are the writings of Peter Aggleton, Hilary Homans, Cindy Patton, Ian Warwick, Simon Watney and Jeffrey Weeks. *Social Aspects of AIDS* (Aggleton, Homans, eds. 1988) is particularly good as an introduction to the research work of most of the above. It includes a chapter on 'Health Education, HIV and AIDS' (Homans, Aggleton), alongside that of 'Young Peoples' Health Beliefs and AIDS' (Warwick, Aggleton, Homans). It deals with many of the issues of the third epidemic in 'AIDS: "Moral Panic", Theory and Homophobia' (Watney); 'Love in a Cold Climate' (Weeks). It also examines the role of both government and media in perpetuating myths, as to the realities of the virus and syndrome in 'Perceptions of risk: media treatment of AIDS' (Wellings) and 'Visual AIDS: advertising ignorance' (Watney).

Aggleton and Homans have also produced an excellent document *Educating about AIDS* (1987), intended for community physicans, health education officers, health advisers and all others with the responsibility for education about AIDS. Aggleton, Horsley, Warwick and Wilton have produced very inciteful work in *AIDS: working with young people* (1990) and there is a particularly good article to be found in the *The Health Education Journal* (Vol 48, No4, 1989): *HIV/AIDS education in schools: constraints and possibilities*.(Aggleton).

Alongside these writings, useful resources are to be found in *AIDS: scientific and social issues* (Aggleton, Homans, e al, 1989) *AIDS: social representations, social practices* (Aggleton, Hart, Davies, 1989), with a specifically good resource for reading about HIV/AIDS education in relation to policy development being that of Aggleton's *AIDS: individual, cultural and policy dimensons* (1990).

I have referred to the research of Cindy Patton, journalist and academic, throughout this thesis, finding her philosophy of education and insight into the epidemics, an incredible source of inspiration. Her initial work, *Sex and Germs: the politics of AIDS* (1985) is, in my opinion, the work of a researcher well ahead of her time. It can be followed by an examination of our perceived roles as 'victims' , 'volunteers' and 'experts', in the face of the epidemic(s); a particularly pertinent paper being the one she presented at the Institute of Contemporary Arts, 'The AIDS industry: construction of victims, volunteers and experts' (London, March 5-6, 1985). Patton further examines the reprecussions of the third epidemic in *Heterosexual AIDS panic: a queer paradigm* (Gay Community News, 9 Feb, 1985) and provides a foundation of resistance and self-empowerment in *Resistance and the erotic: reclaiming history, setting strategy as we face AIDS* (Radical America, Vol. 20, No.6 1987).

Patton's research into the language of AIDS and its metaphors is well defined in *Inventing AIDS*, [1990], where she uses the techniques of literary and contemporary social theory to reveal that AIDS discourse is 'not only about people, but about power, homophobia and discrimination'. Her work has been particularly pertinent in the writing of this thesis, in referring to how we 'formulate public policy and political strategies to resist [all] forms of oppression, acompanying the epidemic[s]'. Patton is particularly interested for example, in bringing to the forefront of her research; the 'hidden voices' of the epidemic(s) and the 'reasons for their suppression from the present discourse on AIDS'.

Susan Sontag provides an excellent incite into the use of language and metaphor in her work of the same name, *Illness as a metaphor* (1978). Her subsequent work, *AIDS and its metaphors* (1989) furthers her critique of the use of language and its power to dehumanise those living with the virus and syndrome, while illustrating the societal fear and prejudice that are so inherent in the repercussions of the third epidemic. Both of these are very good for examining our own use of accusatory and disempowering language in relation to illness and can be found published together in the more recent (Penguin, 1991) edition.

The Panos Dossier *The third epidemic: repercussions of the fear of AIDS*, [1990], goes a little further to examine the reactions and response of whole peoples to HIV and AIDS over the past ten years, and on a more global scale. It examines how the reactions to the virus and syndrome can be just as destructive as the virus itself and describes some of the many acts of prejudice and hostility experienced by people with HIV/AIDS and why they might arise. The dossier also looks at issues surrounding HIV and AIDS in the workplace, different government responses to the epidemic(s); alongside HIV/AIDS, law and human rights. This dossier also includes an appendix which details the extent of the first and second epidemics on an international scale, (1990).

Simon Watney (1989) examines issues pertaining to the third epidemic in his own investigation into the role of both the government and media, specifically in the area of censorship. *Policing desire: pornography, AIDS and the media*, (1989) is very informative reading; as are *The rhetoric of AIDS* (Screen, Vol 27, No 1, Jan-Feb 1986) and his discussion of *AIDS, language and the third world* (Taking liberties: AIDS and cultural politics), Erica Carter, Watney, eds, 1989. He examines the 'Spectacle of AIDS' in: *AIDS, Cultural analysis, cultural activism* (Crimp, ed, 1988) and discusses issues surrounding 'Safer sex and community practice' in the excellent resource *AIDS: cultural and policy dimensions* (ed Aggleton et al, 1990).

For an examination of the beliefs and attitudes of young people concerning HIV and AIDS, I have found the work of Stephen Clift very useful. His chapter on 'Blame and young people's moral judgement about AIDS', (also to be found in *AIDS: individual, cultural and policy dimensions*, Aggleton et al, 1990), is a very good introductory reading. This can be followed by his (and Stear's) study in a British context, *Beliefs and attitudes regarding AIDS among British college students* (1988) and their *Survey of AIDS education in secondary schools* (Stears, Clift, Horsham, Avert, 1990).

White has also conducted some interesting research into *Adolescents' perceptions of AIDS* (1988); as have Di Clemente, Zorn and Temoshak in their earlier, but informative study *Adolescents and AIDS: a survey about knowledge, attitudes and beliefs* (1986).

An excellent study of young people and AIDS is to be found in Felicity De Motta's work *HIV/AIDS and young people* (unpublished thesis, Institute of Education, University of London, 1994) and that of Warwick and Aggleton's *Adolescents, young people and AIDS research* (1990).

For those specifically interested in the perceptions of primary aged school children, the work of Farquhar is an excellent introductory resource. *What do primary school children know about AIDS?* (1990) looks specifically at their own perceptions as does *Safer teaching or safer sex: primary teaching in the age of HIV/AIDS* (1990); but with the latter looking to the attitudes and role of the primary teacher in the health education process. Philippa Russel's *For Adults only? Confronting the implications of AIDS for children and young people* (1987) is an earlier study, but very perceptive in its analysis of the specific issues relating to the needs of children and the role of education and social services in educating them. This article also looks at the implications for agencies and families caring for children with AIDS and 'the need for accurate and honest health education for [all] children'.

There is an abundance of literature pertaining to the strategies required for the successful development and implication of HIV/AIDS education in schools. I have found the work of Nick Freudenberg very useful, in looking specifically at the *Social and political obstacles to AIDS education* (1989); while Gabriel examines *Pupil identification of curricular needs: defining a programme on AIDS* (1991/92). Kirby presents well, research on the *Effectiveness of sex education programmes* (1989); as do Clift and Stears in their *AIDS education strategies for young people* (1987). Hornick presents evaluation strategies, together with some interesting case studies in *Evaluation strategies: comparable findings from Australia, Sweden and the United Kingdom* (1987).

Other case studies of successful HIV/AIDS education praxis can be found in Clift and Stear's [The] *HIV/AIDS Education and young people's project* (AVERT, 1989); Gillie, Stork and Bretman's *Streetwise UK: a controlled trial of an AIDS education comic* (1990) and in Sasha Alyson's *You can do something about AIDS* (The STOP AIDS Project, 1988). Aggleton's work is also an excellent resource, as previously cited, earlier in this review.

There is powerfully developing praxis to be explored in the field of HIV/AIDS education in Aotearoa/New Zealand. The evaluation of works I specifically refer to in this thesis are those of Gillian Tasker's 'The effectiveness of a teacher development programme in empowering secondary school teachers to develop and implement quality health/HIV-AIDS education in their schools,' 1992-93; Forrest Chamber's 'Schools project', 1991-93; and Geraldine McDonald's study of the New Zealand Combined Colleges of Education, *HIV/AIDS - sexuality education teacher development programme*, 1994. The NZ Strategy on HIV/AIDS, 1990, along with the research of the NZ AIDS Foundation are definitely invaluable research resources in an Aotearoa/New Zealand context.

From a cross-curricular perspective, teachers can introduce young people very successfully to HIV/AIDS education, through the use of literature. Sandra Stephan provides an excellent education resource in *Literary AIDS in the composition class: teaching strategies in confronting AIDS through literature*, (from Judith Pastore's *Confronting AIDS through literature: the responsibilities of representation*, 1993). McQueen and Fassler also offer a review in *Children's books about AIDS* (1989); as does Brodsley in *Teaching about AIDS and plagues: a reading list for the humanities* (1993).

The successful use of drama in HIV/AIDS education has been well documented, alongside that of peer education. As previously cited, the work of the National AIDS Trust 'Living for Tomorrow Initiative' (1990-91), is an excellent document, describing the HIV/AIDS education praxis employed, together with the voiced perspectives of the young people involved.

McEwan, Bhopal and Patton also discuss the evaluation of their own praxis in *Drama, HIV and AIDS: an evaluation of a theatre education project* (1991); as does Loveless, in a wider community context in *An evaluation of the drama-based education project in youth clubs* (1992).

The value of student discussion and peer education can be examined further in the work of Boyle (et al) in *Exploring young people's attitudes and knowledge of AIDS: the value of group discussion* (1989) and through the research of Lynch and Hamilton in *Peer training and HIV education* (1990) and that of De Motta (1994), as previously cited.

For those ready to create their own HIV/AIDS drama education praxis specifically within the primary/secondary school context, the work of Dorothy Heathcote, *Collected writings on education and drama* (1989) is an excellent introductory resource.

I introduce some of the concepts of drama education as espoused by Augusto Boal in this thesis, finding his own philosophy of drama education in *Theatre of the Oppressed* (1993) very inspiring; although *Playing Boal, theatre, therapy and activism* (1994) is definitely a more accessible resource, for those wanting an introductory discussion of his drama methods and concepts, in attempting to incorporate them into their HIV/AIDS health education praxis.

I found the work of Tamsin Wilton's *Antibody Politic* (1992) very good reading in the initial stages of my own research process; particularly her chapter on HIV/AIDS in relation to women and her discussion of AIDS and racism. Wilton provides an excellent analysis of press coverage (from a British perspective) in *Fire and Brimstone: Press coverage of AIDS and its consequences*; some of which could well be used in classroom discussion of the facts and fiction, pertaining to all three epidemics. Teachers could well develop their own resources from press coverage in an Aotearoa/New Zealand context; the appendices of Wilton's work also providing information on safer sex and drug use, together with one on further reading and information sources.

Finally, I found the writings of Larry Kramer *Reports from the holocaust* (1989) and Randy Shilts' *And the band played on: politics, people and AIDS* (1988) very interesting, although at times, slightly sensationalised, initial accounts of the development of HIV and AIDS in an American context; with the work of Erica Carter and Simon Watney *Taking liberties* (1989) and that of Act Up/New York *Women, AIDS and activism* (1990) becoming my constant companions as I began my own research process to record some of the very many positive and courageous voices of the HIV/AIDS epidemics, London/New York 1992-94.

APPENDICES (ii)

Paul's Poem

Charlene (Case Study)

Richard (Case Study)

The Eagle & The Wolf

here is a
great battle that rages
inside me.

One side is the soaring eagle.
Everything the eagle stands for is
good and true and beautiful, and
it soars above the clouds. Even
though it dips down into the valleys,
it lays its eggs on the mountaintops.

The other side of me is the howling
wolf. And that raging, howling wolf
represents the worst that's in me.
He eats upon my downfalls and
justifies himself by his presence
in the pack.

Who wins this great battle?

The one I feed.

By Paul Fore

Charlene's Story (Section One of Interview)

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Charlene My name is Charlene. And I'm doing a '3-by-6' for the [AIDS] quilt. One for my mother. My mother died from AIDS. There'll be one [quilt] panel beside [it], for people who want to live; who are fighting this disease. And one side, for the people who have died. My friends. [pause]
And, like, I'm feeling so emotional. And it was like, you know, [pause] It means ... a lot to me, to be able to do something like this.

You know, it means a lot to me. ' Cause, I had heard about the quilt... And I just thought that it was so beautiful, you know...Anyway, this panel [here], is for my mother.

And [pause] I'm going to put the lace around ... [this here]. My mother was a seamstress, so I figure there's all sorts of cute little things I could add in here, that would be nice, because she always liked to sew.

I [pause] don't know. I'm just going to add [this lace] here. Maybe it'll be shown around the world. [pause] Because my family never wanted to accept it. Maybe even me, myself, you know. Because the diagnosis from the hospital was AIDS. And (pause) I don't know ... it makes me think a lot.

Maybe I also had this [HIV] disease, for 24 years.

Maybe I was born with it, because my mother never...My mother died when she was 42 years old. [HIV] and AIDS, weren't even a thing, when my mother died.

Catriana How long ago did she die?

Charlene My mother has been dead for six and a half years. [pause] And I don't know. It was just real hard to accept. To be able to say that, you know. And I'm just wondering if ...I would like the world to know who my mother was. [pause] Her name was Joanne. My mother was something else.

Catriana Would you like to tell me about her?

Charlene She was...My mother was an alcoholic. And she drank. But I loved her, because she took care of me. All my life. Until the day she died. My mother took care of me. [pause] So, I loved her regardless. For what she did, to what she dreamed. I loved her.

Catriana Did your mother become very sick, very suddenly ?

Charlene Yeah. My mother died within a week. She stopped drinking. She started to have seizures. And then she died. [Pause] Besides that, she went to hospital, on the Friday. She died that [pause] Sunday...at the hospital. And I was in jail.

I came home from jail. I got out, Monday morning. I came home and I asked my sisters where was my mother. And my mother was dead.

I knew I was [HIV] positive. I knew I was positive. But I didn't know [pause] all the things that I know today. I know a *lot* more, today. So, [pause] I didn't have a lot of information. I just knew I had AIDS. There's a world of difference.

Charlene [So], I had my second son. And he was sick. And they started taking these *tests*. And one of the tests they asked me to take was the HIV test. But I allowed them to take it. And my son came up positive. [pause] Both my sons, as well. So [pause] that was hard. That was hard.

I wrote for my mother. I wrote for my mom. Then six months later, after my second son was diagnosed with HIV, I lost my mom. And I went on one big stupid drug run. Just doing drugs and not caring...Till I got myself clean. And then I learned more about being HIV positive. And how to take care of myself, you know. [pause].

[I learned] that I didn't have to be on drugs. That I could [pause] mourn my mother without trying to -
Because that's what I wanted to do. I didn't want to live anymore. I wanted to be with my mother. 'Cause
I didn't know how to care for myself. And she took care of me, for so long. And when it was time to take
care of myself. I didn't know how. I just wanted to -

I never really got over my mother's death. I still haven't got over my mother's death. I just live [pause]
today. You know, I live for the day. And [pause] I cry a lot. I cried today, when I started making this
quilt. You know [pause] I just deal with the feelings I'm going through. And I don't have to use drugs,
behind it. So, that makes it easier to do...knowing that I don't have to use drugs.

[long pause]

To feel my mother, you know. To escape the feelings with it... I don't have to use drugs to kill the pain.
Because the pain is not going to go away, that easy. [pause] So, I just get to stay clean. And do things,
I'm working for.

[long pause]

Catriana How did they tell you that you had tested positive?

Charlene They gave me no counselling. No nothing. It was February, 1987...I was 13 at the time. When they told
me, the doctor was like...When I called for my results...See, I didn't know these results were
confidential... and I guess the lady who gave me the results on the phone, she didn't know these results
were confidential either.

So, she gave me the results, over the phone. And then she said: " Well, I'm not supposed to give you the
results over the phone, so you'll have to come in."

So, I came in. And the doctor told me. That I was positive. And that it was alright to cry.

And that was it.

You know, " It's OK to cry, Miss C -" And it was like, real plain and simple. [pause]. So I *cried* .

I cried. And I didn't know why I was crying. I didn't know what the disease *was* . I didn't know what I was crying for. I just knew I had [pause] *something* . And they didn't have a cure for it.

I didn't know that people were dying all over the *world*; that children were dying all over the world; that my generation was wiped out [pause] from AIDS.

Interruption: Charlene wants the tape stopped and indicates when she wants the recording continued.

I have to live my life for today. When you use drugs, for *so* long, you get tired of being like that. So, you have to find a better way to do it. And I found a better way. Staying clean. Working the programme; doing what you have to do for yourself. And that's where I get my strength, by not wanting to be out there, no more. And I know that if I go out there...and get high...I'm going to be dead.

So, I have a choice: either I live or I *die*. Because I can't do drugs, with this disease. If I do drugs with this disease, I'm going to die. And that's the bottom line. There *is* no coming back. There is no: " Oh, Charlene, you can do it for a few more months, and everything's going to be alright."

[pause]

That's not real for me. What's real for me, is seeing if I go out there and smoke any more crack, you're gonna die. 'Cause my body can't take it. So, [pause] I stay clean, the best way I know. One day at a time.

Charlene's Story (Section Two of Interview)

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Charlene I've had three relationships. Whenever I get into relationships, they seem to last forever.

My first relationship was for five years. I was thirteen, when I met him. He was twenty-one. My mother told me not to do it. But I did it anyway. It was a very abusive relationship...He beat me. ...I learned to fear him.

You know, when I did want to end the relationship, I was too afraid...to not see him...Afraid that he was going to beat the hell out of me. But I loved him. And...

I left him. I finally got enough courage to leave him. I met my friend's father. And I found the courage to leave him.

My second relationship was with my friend's father.

A very abusive relationship. We were abusive to each other, in the end. I stayed in [that] relationship, because I loved him...I was very *young*. I wanted to be with a man...Then I learned how to let go. He became obsessive. And I had to let go, for fear of my life. And I let go. And I moved on. But I never stopped loving him. And that's what I was saying before -

[interruption]

...Yeah. [laugh] You know what I think?...Sometimes you have good times. And sometimes you have bad times. But...well, I wasn't on crack, at the time. But I was on drugs. And drugs make you do things, that you wouldn't normally do...It takes you places that you don't want to be.

So, when I learned that, then I was able to forgive. Never forget. But I was able to forgive those things ... that they did to me....And that I did to them. Hopefully, they forgive me, for the things I did to them. Because it wasn't me. It was the drugs. So...

[Charlene asks for the tape to be stopped and indicates when she wants recording continued.]

So, now. Here I am...My son is...He will be seven, next year...You know, six and a half years down the line. And I keep wanting to tell him...[my son's father]...You know, no matter where we go...Or where we are [his father and I] always find each other. You know, this thing is *deep*. Because, it was so bad in the beginning...I knew there must be something more. There must be something good that can come out of this.

So, [anyway] ...my third relationship...[By] my third relationship, I had a daughter. My daughter is ten months old. *Non-positive*. But you know...And as I said, I was in that relationship for five years. No one thought it was *not* a healthy relationship. ...It started out great. But he was active. And I didn't know it. And I was trying to stay clean. And I moved out. And gave up my recovery for him. Something I will not do today. I will not give up my recovery for anyone. Not even my children.

Today I've learned, to let go. I've learned to be able to accept, that if something doesn't work...[you know]...Then leave.

...Leave it alone. Don't try to fix it. Just leave it alone. And it was hard to accept, because I love him. Being with him is like smoking crack...So, it's either that I want to live. Or I want to die.

You know he, [my third relationship] ...he's sick. He's dying of this [HIV virus]. He's dying of this. And it's really hard because...when I get sick, I want someone to be there for me. So, I'll be there for him...You know. I'll go to the hospital. I'll visit him. I'll talk to him. I try to keep his spirits as high as I possibly can. And that's hard because...*I'm* living with this [virus]. And it's scary, because he's sick. And I have to *watch* him...slip away...And the reality, for me is...One day..I'm going to be like that.

[Recording is stopped]

You know...my friend always tells me:

"Charlene, you've watched all your friends *die*. Now you're watching your daughter's father *die*. Are you gonna die this kind of way?...Are you going to suffer?"

You know...Sometimes I ask God...You know...What have I done, so terrible? [pause]...to have... to suffer like this? That's the question I have, that I haven't got an answer for. And people say: "This is *not* a curse!" - You know -

[Well], I don't want to die. I'm off drugs today. It's easier, if you want to survive. Because, you're not going to fucken survive, like this [otherwise]...Because cocaine breaks your body down. And it just gives [HIV] more room to move around. And I don't have that time...to let it move around. And *I* don't have that time...to let it move around me, like that. You know, I've watched so many of my friends die.

And today...[Today] I did the *AIDS quilt*...[pause] And they were like -

"Well, you can have this little space" [for your memorial panel] And I was like: "I want a *twelve-by-twelve*."

'Cos I've lost *so* many people to this disease, you know. And I want the world to *know*...this is *what's* happening. PERIOD. You know.

We [just] can't say that this is a gay disease. Or that people get it, because they do drugs. Or people get it because they don't listen to their mothers and fathers. People get it. People *get it*. There's no reason. It just happens. Shit happens... For no reason at all, I feel, sometimes. [pause]

[See], I know I contracted this disease, when I was 13 or 14.

[Long pause]

Catriana Because of your first partner?

Charlene Because of my first child. I'm 23 years old. I had him when I was..I got pregnant, when I was 15. I had him when I was 16.

[Interruption]

My first child is 7-8 years old. I had him when I was 16 years old. I started having sex when I was 13.

So, between the ages of 13 and 15...

I got [HIV] before I was 15 years of age. Say, 13, or 14... I was, [whisper], a baby.

[pause]

I mean, there are young people, who don't realise that. [pause].

[So], even if you think your partner's done drugs...you know...Or, your partner's never been promiscuous...Well, if he's ever had sex without a condom...he's a high risk. You know, I don't care who he's been with. He's a *high* risk. you know. And that's that. Because a lot of them have it. And they don't know they have it. And they're giving it away.

And I don't want to give this disease to anybody. [pause] Nobody. I'm never going to let anybody go through, what I have to go through on a daily basis. Because it's not an easy thing to do. It's really, really hard.

I know its hard for me: yes, I smile. I laugh. I joke...But this shit is hard.

You know, in other ways, it's easy, when you don't have to think about it...But [then], when something happens...like the AIDS quilt...And, it's like - right there in your face...[pause]...You have to deal with it. You just can't stuff it, anymore. It just comes all out.

I was overwhelmed, with all the names of the people, who have died, from this disease. People who are living with this disease...And I was so sad. You know [pause] I was so fucken sad.

And I thought "*Why?*"

What *have* we done *so bad*, to have to suffer so long...so hard.

[long pause]

Tape recording is stopped

Our conversation continues after this cut to the taped interview.

We talk of Charlene's mother, her late diagnosis and sudden death to AIDS. We speak of Charlene's own (HIV) 'status' and that of her first and third partners. We also speak of the discovery that two of her three children are (HIV) positive.

The taped recording of this interview does not resume, until Charlene indicates. (She is also aware, that it need not continue, at all. Or that it can be stopped again at any stage, she chooses)

Catriana Do your children understand about HIV?

Charlene They're too young to know. I mean, they're too *young* to know. They *don't* know. I hope they find a cure, so they never have to know...[pause]...[to know] what they have. ...What this disease can do, physically and mentally.

Catriana If you wanted to, were you able to talk to anyone else about discovering that you had also tested positive?

Charlene Yeah...It was hard for me. It was easy for me to tell my family. But, it was hard for me to tell my friends...Especially two close friends. Their brother had died of AIDS. And I still hadn't told them...And when I told them, [My friend] was shocked. ...in the beginning. She didn't even say anything. Just went on with the conversation. And a week later, I received a letter in the mail, from her. And, you know...she expressed to me, how much she loved me. And she didn't care what I had. She would always be my friend.

And it got to the point where, if I couldn't travel, she would send a cab for me. You know, she would scrape up the money, to *get* me there. [pause] No matter what condition I was in...And that was real touching for me. That was easy...It made it so easy for me to say: "OK, well...I have [HIV], but they love me anyway," [pause] So...people shouldn't be afraid of what anyone else is going to think of them because *we* have to live with this disease. Not everybody else.

Catiana You seem to be very positive about your life and all that has happened to you. Something I have noticed about the people I have *interviewed* here, in New York, is that, in the face of all the difficulty and prejudice, people's acceptance level seems to be so high -

Charlene Well, it's so high - [Laughs] - because every god-damned body *has* it. [Laughs out loud.] No. No. It's just because, it's *so known*. You know, [Still laughing] You know if people want to be educated... [pause]...And you know, that's about the only thing... That's about the only thing we can do...is educate people, to let them know, you can't catch it...from kissing...or from hugging, or sweat. You can get it from blood transfusions; from sex or drugs. And that's the only way you can [get] it....You know...but some people still don't realise that. People still think you can [get] it from sitting on a toilet seat. Or [from] touching; or hugging. Or someone's tears. And that's just not true. And until we educate these people, and let them know, you can't [get] it just like that...[pause]...it would be a better world ...for us to live in.

It would be much easier for people to accept this disease for *what it is*: A *disease*. And not a curse, of some kind, that God has sent down on us to wipe us out.

That's not true. Children are born with this disease. And they haven't even committed a sin. They die before 5 years of age. What did they do? Nah.. Let somebody ask: What did they do to deserve this?

Richard has been sitting with us, on the stoop of 145W 130th Street and now speaks for the first time in the interview:

Richard I kind of figured. - This is gonna sound funny. [pause] - I kind of figured, it was something that I got because of everything I did wrong, you know. [pause] And sometimes I still feel like that. I'd done a lot of wrong things to a lot of people and I figured that...What comes around; goes around. I thought that was my [pause] payment for all the things I did to people. [pause] It's kind of weird, because I still feel like that now, in a way, you know. For all the things I done, I figured that something was bound to happen to me, sooner or later. [pause] I just thought: somebody's going to kill me, you know. That's the way, I thought it was going to happen. I thought maybe somebody's going to kill me. And maybe, [turns to Charlene] - maybe I thought you might kill me. At times, I'm still surprised that you'll even sit down and converse with me, if I can think about it -

Charlene Yeah. You done a lot of things -

Richard You know, it's not only with her [pause]. I was in relationships where I didn't do anything wrong, and was beat up. Just beat up. And I mean, This girl, literally kicked my ass, for a year and a half. And I wanted to hang out with my friends, you know. I spent all week with her. And on a Friday or Saturday, I wanted to hang out with the boys. And I told her; "No. I'm not staying in the house with you. I'm going to hang out with the boys." I seriously got beat up...No seriously...I'm not trying to be funny. You know, I believe in that story-book romance-type stuff. Get married. Have a little house, with a picket fence - [pause] I still believe in that now. [pause] And I'm going to get that. One way or another. I'm going to get that. I don't care if I'm ninety years old and [pause] that's when I accomplish that. Then I'll be happy. Because I accomplished something I set out for.

Charlene You know...One day I was sitting. And I was talking to somebody. And we were talking about growing old. [pause] And I cried, because when I was a kid I always *dreamed* of growing old. You know. And it was [pause] It was like...being *HIV positive* [long pause] and growing old...It's like, it doesn't work. You know. It doesn't work. And I cried, because, I'm never going to grow old.

Richard Don't say that.

Charlene But that's ...Well, OK -

Richard *Some* people -

Charlene OK - so it's not...But there is a possibility...if they don't find a cure for this disease -

Richard There's a *possibility*, you *might* not grow old...I can understand that -

Charlene I might not grow old.

Richard Shit.

Charlene I might not grow old. And that's something that you look forward to, you know. You want to live to 50, or 60 years old. 70 years old. - Maybe, even 100. And. There's a chance that I may not make it. And you know, I cried. Because, I found that *so* sad. You know, to grow up as a child, wanting to grow old. And then become a teenager. Then, to have that totally wiped out. You know, Steve will never grow old. And that's something everybody should be able to do. To live a full life. And you know, I cried. I cried like a baby. It was like...you know: DON'T CRY. JUST DON'T. If you know that reaction. It's weird.
[pause] It's weird.

[long pause]

But I *do* believe, that when I die, I'm *not* going to die from this disease. I'm *not* going to let this disease take me out. When they have a cure, I'm going to be able to stand up. And get up. And go to get it. I *am* not going to die from this. I *refuse* to let this shit, take me out. I refuse to let it claim my life. I *love* my life. [pause] Life is too precious , for it to be totally wiped out, like that. I'm gonna fight. To the bitter end. I'm gonna *fight* for my life. Because, it's *my* life.

[long pause]

The recording is stopped and continues when Charlene and Richard indicate

Richard I'm going to fight for my life. But I've got to fight *with* this (HIV) thing, in order to have a life.

Charlene You don't have to fight it...[like that]...You just live with it.

Richard I'm not going *to live with it*. I'm going to fight it. People may...[pause] You know, I'm not saying I'm going to lay down and let things happen. But I'm not going to stand by and let it take its course. There ain't no way in hell, I'm gonna die from this hell...I still feel, deep in my heart, I'm gonna die because of something in the streets. You know, because of the way the streets are. Not because I'm going to do something to get killed. *But...*like, the way the streets *are*...[pause] You know, because I know what -

Charlene Well, if I've got anything to do about it, you won't be out on the streets, to die from the streets.

Richard I'm just looking at the - I'm just looking at certain [pause] I just know that the number one killer of black people, between the age of 10 and 34 is guns -

Charlene Well, let me *update* you on that: the number one killer...the number one killer -

Richard Of black males?

Charlene In New York -

Richard Of black males?

Charlene - In New York, for black *women*...is 52%, dying from AIDS.

Richard No?

Charlene The number one killer of *black men*, in America, is 51%, DYING FROM AIDS.

Richard Yeah?

Charlene Yeah. 51%. AIDS is *killing* more people, than violence. [pause]

You know what's even more scary...Our people...I mean, *let alone*, that we have cancer. We have tuberculosis. We have all these troubles...out here. And we still feed *each other* with drugs. [pause] We kill our brother man. Black, White, Chinese, Puerto Rican. We help kill *each other*. We take *each other* out.

Haven't we had enough to fight? Haven't we enough things, out there, to go against us, you know. And we help kill each other.

We have so many young [people], out there, who are selling drugs...to their mothers; their sisters; their brothers. And not even caring, because the money is so good, you know. The fast life. They think it is fabulous. And there's no one out there, to tell them, that this is not a fabulous life: that you're gonna *die*, by the time you're 25 years old. Because either, somebody's going to shoot you. Or, you're going to die from drugs. Or you're gonna die from AIDS.

You know, there's nobody out there, to tell them [pause] that you're going to end up going places that you don't want to go. Doing things you don't want to do. [pause] You know, there's nobody out there, to say these things. And that's the saddest part.

Richard You know I think what...the saddest part...is that they...that they feel that they'll never *get* to that point. That we all think...well... "I'm not going to do this. I'm not going to do that."

Well, everything I said I *wasn't* going to do, I did -

I think if I was going to meet somebody, who was 50 years old; who had lived a normal life, of no drugs. No this. No nothing, you know...And they're living in a real nice area; that they didn't have to get through some of the things I did...I think I'd probably [find I'd learned] as much as they did...with my little bit of time...Because I went through -

Charlene Hell.

Richard I'm still in hell. I haven't made it out yet. But, all I can say, is...it's not *as bad as* it used to be.

Charlene I tried to tell you. You know. I tried to tell you when B was born. And you knew how sick he was.

Richard I knew he had it.

Charlene And you know...I was not afraid to tell you, that I was positive. And that you should get tested. And that...I *knew* you had it.

[Interruption]

Richard Life is so different. Life is so different, now. [pause] The past couple of weeks, life has been so different...My self-esteem is better. I feel good about myself. My job. I've landed two jobs. I was taken to Pennsylvania, to speak to the kids about drugs. And I felt good. You couldn't tell me nothing. But you see...I used to be so shy. I couldn't [even] speak to Charlene. And you see, I'm still shy in many ways. See, Charlene don't know this, but I got a whole bunch of letters that I won't...give her. I write letters.

Charlene [Laugh] I remember, the first letter he wrote.

I was in my bedroom. And, I hadn't even got dressed, for the day. And my mom and my sister were in the kitchen.

And I guess the letter came up, under the door. And my sister picked it up, and read it. And they...read it. [pause] And then they brought it into the room, and told me. And it was like: "Yeah! - Charlene's in love!" And they teased me.

So, for so long, he used to write to me. I used to save them. I have no idea where they are today. But I used to save them in a shoebox, in the closet. And...he writes poems. [pause] And his letters were like - [long pause] They were wonderful. I loved his poems. I loved his letters. They were so sweet and gentle and...[pause] That's the person he is. A wonderful person...who wants a lot of love.

Richard Charlene. She don't know. I think she's wrong -

Charlene I think I'm right.

Richard I don't know. I think...I think I'll put it...I'm a reforming street hoodlum. But she don't seem to see it, like that.

Charlene He's not a street hoodlum.

Richard 'Cause, she looks at the way I dress, now...compared to the way I used to dress...And...this is the thing...I love my boots, my sneakers, my jeans -

Charlene And I hate the boots.

Richard I love the boots, OK?

Charlene I hate them.

Richard That was my way. And I kind of like this...[outfit]...But she doesn't think so.

[Interruption]

Richard I love Charlene, with all my heart.

I disobeyed my mother, - any chance I get - just to be around Charlene.

My mother is a very good friend, that I didn't know at the time. And I might even...Today I might even go against my mother's wishes, to be around Charlene.

Charlene I loved him, till there was nothing left to love. I never learned how to let go.

[Interruption]

Recording is stopped

Catriana If you had anything to say, what would you like to tell other people, who have just tested positive?

Richard Anybody, who has this disease.. I would say, *hold your head up*. The fight's not over. The fight is *never* over. It's not over till the last second, you know. And give up drugs, don't [start]. Don't use them as an excuse to kill yourself. If you're in recovery, don't use that as an excuse, to go back out. Just keep your head up. Keep on fighting. Because, I'm going through difficult times, but I'm not dead. I refuse to die. I *refuse* to die, you know.

I used to be afraid of growing old. But, since I found I have the [HIV] virus, I'm not going to die. I'm going to be an old man. I plan on being an old man, chasing people around in my wheelchair [laugh] at 90 years old, you know.

And I want everyone to know, that this is not death. I've invested too much into my life, to let this little simple shit *stop* me from living...I want to live.

Catriana What would you say to the people, out there, who have never gone for an [HIV] test...Who may never even considered, that they might have the virus -

Richard I would say, *have* the test. - Anonymously, if you like, but have it. It's better to be safe than sorry. Messing about with ...[this], is not the answer. If you have *any* doubt, get tested. There's still something, you might be able to do.

Charlene Yeah. If you get sick, [and the doctors don't know], they don't know how to treat you. They do not know what you have, you know. If you are in a relationship, you could be giving it to your partner, to your unborn child.

If you are in various relationships, you could be spreading the virus. You should do this, *for you*. Do it anonymously, if you like. But do it for yourself.

Catriana What would you say, Charlene, to the people testing positive -

Charlene You didn't get *this far*, today, to stop going. Have a little faith in yourself. Have a little faith. Don't worry, just keep fighting. Because your life is *worth* fighting for.

And watch out for those who want to make money out of AIDS. We don't have to take these toxic medications, the government wants us to take, you know.

There are holistic medications, that are much healthier, for us. That can help us live longer.

You know, we don't have to take AZT and DDI...That's the new one. And it's much more toxic than AZT.

You know, we don't have to take these toxic medications. They kill us faster. And the reason, they're giving [them]...They are giving them to us, because it's money. They make so much money through the pharmacies. Don't take it. Make them *find* a cure.

[And] they're still saying that there is a 'high risk group'. There is *no* risk group. There's only high-risk behaviour. And it's a fact, that if you're having sex without the use of a condom...I wouldn't care if you were with your husband twenty-five years...[educate yourself].

Richard I was one of the ones, who looked at certain 'at risk groups'. I figured...I was one of the ones that thought: "If I can single out...you know...to protect me...I'll be OK!"

After I got tested the first time...[and did not test positive], I started, stone-cold, educating myself, you know. [pause] I knew what to do. I just didn't apply it. You know...it didn't really apply *to me*. You know, I was able to sit down, and converse with everybody, about it. I was good at giving advice. But, I was hard at taking it. I was like a doctor. I could cure you. But, when I'm sick, and you want to cure me, I like, didn't want to take the medicine, as they say.

You know, if there is a risk group: I think *they are* the risk group, the ones who don't look like they have anything.

Richard's Story

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Richard I'm Richard. And I'm 27, [pause] I contracted the [HIV] virus... by doing a lot of risky things. And I really didn't care, 'cause at the time I thought, you know, nothing can happen to me - [pause] I didn't think I could catch [HIV]. Not me, of all people.

I was going to classes. Seminars. And I learned about it. I was very active in the class and me and the teacher, used to sit down and talk a lot. And so I figured I wouldn't catch anything, you know. Not me. [pause] But I learned the hard way. That I can get it. I think I...it was crazy. I was crazy.

At first when I found out, I went through a real bad stage you know. I found out on the 12th of this month, [August 1993] and [pause] I stayed in the house. I stayed in my room. I wouldn't come out...I wouldn't come out... [pause] I wouldn't talk to anybody or nothing. You know. And [pause] I still go through changes now, you know.

I deal with it better, because I've talked to friends about it. I let friends know, because I'm not...I've never been ashamed of anything that's part of me. If it's part of me...if you're my friend, you accept me for, you know, who I am and everything about me. If not, - Hey, forget you. But, I [pause] wouldn't go outside. You know. I mean, I actually stayed in bed for the first three days. Wouldn't eat. You know. I just stayed there. Lay in bed. When I woke up, I just woke up and lay in bed. And my friends [pause] they thought I was doing something else. They thought that I was...that I'd picked up [drugs]. They thought I'd started getting high again. They was like: "We oughta give you a yelling". And I was like: "Well, you can. I don't care." You know. "I really don't care what you all do."

[Then] one of my friends came by. Asked me what was wrong. 'Cause he knew that I didn't pick up. And he asked me, what was the matter. [pause] And [pause] you know, I told him. He didn't care...But like, when I told him, he didn't like, [pause] shy away from me, or anything like that, you know.

He still remained my friend. And because of him, I got the confidence to talk about it. To tell other people. And now, you know, [pause] almost everybody knows.

The only person I didn't tell is my mother yet. Because, I know...She told me...She said "You better watch it."

Because she knew what I was doing. And she saw the change in me, when I picked up drugs. She saw how I was running around, messing with everybody.

So, she kind of knew [pause] something was going to happen soon. And she kept warning me.

Catriana What do you think her reaction would be, if you told her you were [HIV] positive?

Richard "I told you so."

Ah, she'll probably be hurt. She might be upset and hurt about it. [pause] I know she'll be supportive.

Or, at least, I hope she'll be supportive. My mother was always the supportive type. [pause] And I guess, I haven't contacted my brother. I don't keep in touch with him. I don't keep in touch too much, with them, anyway.

But with this, I refuse to talk to her. I know they're wondering if the fuck I'm alive. Usually [pause] I call...you know. I won't be on the phone two or three minutes. And it's: "Hello, how are you doing?" "I'm OK." You know: "How's everybody else, doing?" and then it's "I'll call you as soon as I can."

And now, I don't even do that. I just [pause] I don't know. I still isolate. I [pause] I isolate a lot.

Long pause

Catriana You're doing well. Really well, for three weeks -

Richard Well, I don't think I've gotten over the shock, yet. I've gotten tested. I've gotten re-tested. So, I'm sure.

It's confirmed. I'm supposed to be at a clinic. I don't want to know my T-Cell count. 'Cause I don't want to know...how bad off I am. [pause]

Now, it's kind of strange because since I found out...I've been staying, you know...Girls, I used to talk to...I don't talk to anymore. I stay away from them, and now it seems like...shit...*they're* approaching me. Like, a lot. And I find that real hard...You know, my ego has taken a real bad beating, behind this. Because, [pause] I don't know. I used to think it was all about me, you know. I actually thought it was all about me. And I felt good about that, you know.

That's...the first time I started feeling good about me 'cause I never had high self-esteem, or anything like that. [pause]

I was shy. I was scared of girls, till...much later. And when I went to school, Upstate (New York), I pulled out because of shyness. And I was brushing with everybody. 'Cause I wouldn't have any girlfriend. I would talk. I would talk to this girl. And if she didn't want to be my girl, I didn't pay it any mind, because I had this [idea] that if she wouldn't, someone else will. And I went on like that.

And then my attitude and my actions, started going around, like that. [pause] I was...[pause] part of the world. And I didn't use protection. That's the truth.

That's what pisses me [off] about it. I knew what could happen. But I didn't think that I could catch it.

I thought I could spot the people that would be a 'high risk'. And I didn't know, that by doing that, I was creating risk.

Catrina How did you react when they told you, you had tested HIV positive?

Richard I laughed. [pause] I laughed. I thought it was lying. I laughed for about 5 minutes. And then I sat there crying, for about 2 hours.

The guy sat there, talking to me, for about 2 or 3 hours. I cried for along time. I cried for, say, two-thirds of the time I was talking to this guy, who gave me my results.

Catrina How did he give the results to you, at first?

Richard "I want you to know that you're positive." And he said: "How do you feel about that?"

And I laughed in his face. I *seriously* laughed in his face.

pause

Richard I said: "Not me." You know. "Not me."

And then, after I got that out of my system. I cried. Like a little baby. And I cried for a *long* time.

[pause] And I still cry about it. You know. I still cry about it. [pause] 'Cause I figure, I'm young.

[pause]

You know, when I started getting high, I didn't care if I died. I always wanted to die like my uncle did. He died using [drugs]. He died at a young age. [pause] And he said he was never going to make it to 31. And he died a couple of months before he got there. And I always. I always wanted to get out, like he did. You know. And for me...to change my ways, [give up drugs], and to try and change my life...was hard enough.

[But] then, to be hit by this...That was a real blow. And now my ego was real shot, because I couldn't run about, and mess with anybody like I wanted to, you know. [pause]

[Now], I usually keep a piece of paper in my pocket that says I'm positive. You know. Just in case. You know, if I'm in an accident of something, I can pull this out, and let them know.

I've got to think about other people. You know, I was real selfish. I'm still selfish. Very self-centred. I still think it's all about me, in a lot of ways. You know. And now I have the responsibility of...I'm positive, you know...And with me, I never cared about precautions. I was like, God, as long as I didn't get the girl pregnant...and [pause]

I just realised something I used to think about. I always figured, if I catch something, I can go to the doctor, to get a shot. And it will be cleared up in a couple of weeks. And that was my mentality.[pause]

For a long time, you know: get a shot. And you get fixed. You know. And if they couldn't give a shot, they would give you some pills. You know, I didn't learn. I didn't learn.

...[So], I took the test. And then I came back again. I laughed.

[That guy] he said "Are you OK, Mr S?" "Yeah, I'm OK." You know.

I laughed. And then: "Are you sure you're OK?" And then, like [pause].

For some reason, I wasn't sure...Like in the times before I had the attitude: 'I'm OK. I know I'm OK.'

You see, the last time I tested, I didn't have it. And I thought: "Yeah, I'm not having this."

And lo and behold - I have it.

I've had to back off from people. I told my friend today...because he's messing with this girl. And I told him. I sat down and I talked to him about it. He thinks he knows everything about (HIV) ...like I thought I knew everything about it.

And I told him "You don't know everything." And it was, like "I know enough." And I said: "I knew too. And look what happened."

I *knew* enough. [pause] But I was too smart for my own good. I could sit there and talk to people about it. Tell them what to do. How to take precautions. But I was too stupid to take precautions for myself...because I just *knew* the people I was messing with, didn't have it.

The interview is interrupted here.

Richard's voice is heard again, while he, Charlene and I sit on the stoop of 145W 130th Street, 30.8.93.

APPENDICES (iii)

She made her brother smile

A three minute forum experience (Boal)

SHE MADE HER BROTHER SMILE

A three-minute forum theatre experience

Augusto Boal

In September, 1989, I was invited to give a workshop for the Brazilian Congress of Street Boys and Girls in Brasilia, in the Mane Garrincha Stadium. Owing to a certain unavoidable disorganization at this kind of meeting, I ended up with only half the time initially planned for.

In ninety minutes I had to do theatre with about eighty teenagers ranging from ages 12 to 17. They were a restless and noisy group that had never been to the theatre before. My job was to show them something useful that they could manage later without me or anyone else. Of course I thought of forum theatre. Since there was no play or scene that would serve as a model, I decided to do the three-minute forum.

I started with a question: "What is theatre for you?"

Their answers referred to television, the only theatre they knew about. But they were talking about all kinds of theatre.

"Theatre is being able to invent life instead of just being carried away by it."

"Theatre is learning what we already know."

"Theatre is seeing everything on a bigger scale."

"Theatre is the profession of actors."

"What is an actor?" I asked.

"An actor is a better person than we are because we can live only a single life whereas they can live many lives within one lifetime."

"Why? How?"

"Because they studied how to do it."

Then the only difference between these boys and girls and television actors would be that the actors studied. "What did they study?" I asked. "Is it something very difficult?"

"They studied how to walk back and forth without banging into furniture. They studied how to speak forcefully, and how to cry and show tears so that we can feel sad, and how to laugh a lot so that we can feel happy."

In their own way, the children were telling me that actors were people who had studied how best to use their bodies. I suggested that we try out some physical exercises like the actors did, just to amuse ourselves. Then we would do some image games – mute dialogs consisting of imagery brought up to the stage by the participants themselves, using their bodies, the tables, chairs, and other objects found in the space. We played. Afterwards, I asked them what theme they would like to base a play upon, supposing they were actors. To reassure them I stressed that we weren't going to do theatre – we would "pretend" to do theatre. In unison they yelled:

"Violence!"

"Family," suggested Debora.

After some hesitation, they all agreed: "Family and violence, it's all the same thing."

I found it odd that those children wanted to discuss family as a theme – precisely the one thing missing in almost all their lives. They were homeless children, living in the streets from one day to another.

I asked Debora to come up with a family picture. She showed me familiar characters: a drunken father, a housewife, a drug addict brother, another brother turned religious having conversations with God, and she herself hustling the streets. Debora was 14 years old. She already looked like a tired hooker. Her images reflected her disillusionment, her sadness.

I asked whether someone wanted to change the picture, to suggest some other possibilities, but they were all happy with it: "It's exactly like that! That's family!"

I then asked the actors to speak their thoughts aloud for three minutes, still remaining within the picture and without moving – that is, each one should put into words the thoughts of the character they were representing. The next step was three minutes of dialog *between* the actors, again without movement. The third step consisted of showing through body language all their wishes; all the thoughts that arose should now be expressed as gestures in movement. Beside each actor I placed a boy or girl who would listen to their partner's thoughts in case they forgot them.

This procedure prepared the actors for the forum theatre that then took place. What had first been a simple sculpture, a frozen image, was

now a scene brought alive by the individual characters they had just created. All the actors knew their characters – they either identified with them personally or recognized them as the "other."

I explained the rules of the game and asked which of the characters should play the protagonist who would be replaced in the scene. They said it should be the religious boy talking to God. According to them, he was the character whose change of behavior would modify the family's dynamic the most.

The improvisations now began to take place. With each intervention, I asked only what its special contribution was. And the audience responded, showing what some or all of them had understood or wished for.

"He made the boy talk to his relatives instead of to God who doesn't hear us."

"He made that priest brother of theirs talk to each member of the family personally, instead of offering advice to everybody at the same time."

"He forced the father and the drug addict brother to take some action. He grabbed them by their hands instead of just talking to them. It was the first time that somebody actually held somebody. In this family it seems like nobody touches anybody else."

"He yelled at the father until he finally made him talk. It was the first time the father had somebody to talk to. It didn't matter what he said."

Then a girl came up and made her intervention: She took her drug addict brother by the hand, danced with him, ran, made a clown of herself, twirled around and did somersaults. She wasn't saying anything and, for me, she didn't offer any new solution. In fact, I even thought she might be mocking the entire session with all these grand and comic gestures. I tried to object but the audience resolutely protested against my protest.

I asked them what they thought was the new contribution of this intervention that I had been unable to appreciate.

Debora explained plainly to me what I had been looking at without really seeing.

"She made her brother smile."

It was so little. And yet, for them, it was so much.

Translated from the Portuguese by Ivette Lenard

APPENDICES (iv)

A Sample of the British (NAT) youth initiative programme, 1991

A Sample questionnaire of Gillian Tasker's school development in health HIV-AIDS project, New Zealand, 1992

What happened at each event?

Sample programme.

Living for Tomorrow: Making Choices In Uncertain Times.

Event 5. NORTHAMPTON, 14.2.91. at Derngate

Northampton.

- 9.00: Registration. Coffee on arrival.
- 9.30: Opening by Glna Ogden, Chair of Education Committee.
Introduction to day, Andy Kelmanson, Deputy Director of NAT.
- 10.00: Drama Session. 'Action AIDS'
Performance Incorporating group discussion.
- 11.00: Coffee
- 11.15: Clarifying Information.
3 different workshops.
- 12.15: Humanising the issue.

answer questions.

There were 4 'information' sessions to each day: drama; workshop sessions; meetings with people living with HIV; 2 videos.

The first session was live drama, either performed by a professional company doing work in health education, by a local theatre group, or by a local young people's drama group which had prepared a piece for the event.

In the second session the participants were in 3 groups. One had a talk by an 'expert' (e.g. doctor) on HIV/AIDS, asked to deliver a non-participatory lecture. One had a workshop run by NAT, which involved the young people sorting statements about HIV and AIDS into 'myths and facts'. One had a workshop run by a local educator which involved active participation e.g. Risk assessment exercise.

In the third session they met with people with HIV or AIDS who had been contacted through local or London based organisations. Most had experience of work

**NZ COMBINED COLLEGES OF EDUCATION
SCHOOL DEVELOPMENT IN HEALTH HIV-AIDS PROJECT**

SECTION A: To be completed by teachers and parent representatives working collectively.

Please write your responses in black pen for photo copying.

This question addresses specifically the aims of HIV/AIDS education.

Aims of HIV/AIDS Education	How this is being addressed in your school programme (types of activities, contexts)	At what levels in your school
* to ensure all students are familiar with the facts about HIV/AIDS transmission.		
* to ensure myths, prejudice & unnecessary fears are reduced.		
* to increase compassion for those living with HIV/AIDS.		
* to enable students to assess their own risk & make informed decisions which prevent them from transmission.		
* to encourage the development of social/ interpersonal skills necessary to carry out their own decisions.		

<p>* to encourage condom use for sexually active students.</p>		
<p>* to affirm those students who choose to delay risk-taking sexual activity.</p>		
<p>* to discourage risk-taking drug use behaviour.</p>		
<p>* to foster a positive attitude to their own sexual orientation.</p>		

2. Briefly describe where sexuality education fits in your whole school health programme using the headings provided.

Form level	How health education is time-tabled at this level. Spells per week, weeks per year, curriculum area(s) involved.	How much of health education time is allocated to sexuality education? (spells per week, weeks per year)
3rd		
4th		
5th		
6th		
7th		

3. Has your school developed a school policy for HIV/AIDS?

(i) If YES, what was the development process followed? Please attach a copy of your policy to this questionnaire.

(ii) If NO,

(a) Policy is in the process of being developed. Outline progress to date and future planning.

(b) If no policy development has occurred what have been the barriers in this area?

4. Explain how the involvement of the parent representative from your school has contributed to this project.

5. Have parents (other than the parent representative) been involved in your HIV-AIDS education programme?

(i) If so explain how

(ii) If not what has prevented this occurring?

6. Have other curriculum areas supported you (i.e. teachers directly involved in this project) or contributed to HIV/AIDS education in your school? If YES, explain how.

7. Were you able to achieve the following:

	Yes	No	Facilitated by
1. Whole staff meeting(s) addressing this project & HIV/AIDS education.			
2. Report to BOT			
3. Report to PTA			
4. Report to any other group (please specify).			

8. Have you involved community personnel or agencies in the project? If so indicate below.

Community Agency	How were they involved (staff meeting, students, parents etc).	Comment on Effectiveness

9. (i) What comments do you have about the resources provided for you by this project?

(ii) Are there any additional resources you need?

10. What comments do you have about the ongoing facilitator support provided by this project?

11. How do you believe this project has affected/influenced your school health education programme? (if at all).

12. What do you believe have been the benefits (if any) for the student population at your school?

13. What efforts have been made to address ethnic difference in the school and community in the implementation of this project?

14. How has this project affected/influenced the staff who teach health at your school?

Please add any other comments you may have about this HIV/AIDS project you have been involved in.

APPENDICES (v)

Messages to New Zealanders

Messages to New Zealanders

Right now, people who [do not *have*] HIV or AIDS, are dangerous to the people that [have] HIV. Because the people who are *not* HIV, catch colds. They don't take care of themselves. They sneeze. They have germs.

So, just practice safe sex. And *love* the person that has HIV/AIDS.

Lucy, 40, New York 1993

Live on. First of all, silence = death...It's not a disgrace to have [HIV]. It's a disgrace, not knowing, if you are. It's like, I'm a drug addict and an alcoholic. That's how I got it: through drugs. But it doesn't matter, how you get it. You just gotta live with it. And accept it.

It took me a while to accept it. But I'm grateful, today, that I can live with it.

When I first came here [to Stand Up Harlem], I did not want to be HIV positive. I was angry. I was bitter. I was resentful. I was feeling very lonely. I didn't feel like I belonged here. But...I'm *alive* today. I'm more alive today, than I've ever been. You know, I'm able to be who I am...Good things are happening. You know, there's always hope. You've gotta live on. You know. Keep on living, no matter what. It doesn't mean, because you [have] HIV that you're a disgrace. You're still human. First. Always.

You know, *today*, I know I'm a human being. I have some dignity. I have feelings...just like everyone else. If you cut me, I will bleed, just like anyone else. But I believe now, if I live my life...take care of myself...I can take care of my body, better than some doctors can, because it's my body. And I know it.

The other thing is, if you [have] HIV, then it's best, to *find out*, because, once you do...you can learn how to deal with it. It becomes easier. It's the *not* knowing, that makes it harder.

Howard, 26, New York 1993

It used to get to me a lot, you know...I used to dream about getting sick. You know, if I used to sweat a little, I thought I was getting sick. If I had a cold, I thought I was going to die. [pause] You know, it was pretty scary. If I would sleep too much, I'd think; 'Ah-no, it's kicking in', you know. 'It's coming to get me.' [pause] But, I'm still here, you know. I just didn't die. [pause] And now I look at it very differently...You know, like [pause] if you have HIV it's not the end of the world. You know, people have told me, you can still live the life [pause] of any normal person.

It's not the end of the world...as long as you take care of yourself and leave drugs, alcohol and cigarettes alone. [pause] You can live up to 20 years, with HIV, OK? Then after all those 20 years, *if* you do finally develop AIDS, you've still got another 5 years of life. So, we're talking about 25 years already, OK? And the next stage [could be] AIDS. [But] you're looking at another year...

But that's only if you take good care of yourself. You know, it's like...*don't* put a time-limit on your life. 'Ah...I've got 6 months. God...I've got four months. When is it coming to get me?' Don't put a time-limit on your life, you know. Because if you [do] put a limit on your life, you're gonna *go* faster than you think.

Joe, 27, New York 1993.

Well, maybe you think that you are not a 'risk group'. But there are no 'risk groups'. Man or woman. [Because] somewhere down the line, sex will come in the way. You will want to be with that man. Or, you will want to be with that woman. **Use a condom.** If your man won't use a condom...explain to your man, that HIV is *real*..

Your man might be faithful to you. But somewhere down the line, another woman hasn't been faithful to him. Like, in the same way, a woman will say 'I'm a one-man woman'. But somewhere down the line, that same man has [a history] before he came to you.

So, condoms *are* needed. And there's no such thing like: 'I can't catch it'. Because HIV does not discriminate. It doesn't care if you've got money. It doesn't care if you're poor. And if your not infected with it, you could be *affected* by it. 'Cause you *have* a friend; a sister; a brother; an uncle...

[So] *Don't* reject [people with HIV/AIDS]. *Don't* isolate them.

Don't push them away, out of your life.

You, and they...[may not] to have contact with [IV] drug use... Or anything. But you have contact with sex.

Love them. You cannot get HIV by touching them. If your friend cries, you can't catch HIV from tears. They are not *hazardous* to deal with. They are not hazardous to sit down with.

Lucy, 40, New York 1993.

The more you know about it [HIV], the better.

The knowledge is what keeps me alive. 'Cause, you see, I see knowledge, as power.

Knowledge, for me, is what keeps me alive, because as long as I know how to take care of myself, the better I can feel.

Howard, 26, New York

First of all, the virus does not discriminate. You can be a heterosexual male or female. You may be married. But, as you know, people who are in supposedly monogamous relationships, do have affairs; flings. Or, whatever you like to call them. And who *knows*, who your partner might have [once] been with. At the time, you may both have been tested, and tested negative. But if you have been with someone else, there's *always* the possibility you might be HIV positive. Because this [virus] can take up to 10 years. I know cases, where people used IV drugs. [And] *stopped* for five years. Were tested. Tested negative. Then tested again. And tested HIV positive.

I know someone who was in a monogamous relationship. And her partner did *not* use drugs, intravenously. But one partner turned out HIV positive...It happens.

I've heard people say: 'But we've been together the past five years.' It doesn't matter. If you were in a relationship, *seven* years ago...Who *knows* what that person was doing. You can only speak for yourself. There is a possibility you might [have] HIV.

Phylis, 45, New York 1993.

You know, the way I look at it is like: Well, I'm young and I've got my whole life ahead of me... *as long as I take care of myself*. That's the most important thing [pause]. And, one thing you have to look out for too, that will kill you quicker, is *stress*.

You know, being stressed all the time and letting everything get to you...and letting everything bother you...*That* will kill you [pause] in a second. [pause]

So, I think, the most important thing with HIV, is *not* to put a time-limit on yourself. [pause] You know: don't short yourself.

Or, just because you get a little tired...[don't say]: 'Ah! *This* is it!' You know, its not like that.

You know, there are people walking around here, that have it [HIV] for years. And. And you couldn't tell, if you looked at them. [pause] You know. And it's very deep. I mean, somebody, told me [pause] that your mind controls your body, OK? Your mind can tell your body if you're healthy. Your mind can tell your body that it's not.

And if you stop believing that you're healthy, you're gonna *die*. You *will* die. But if you start telling yourself: 'I'm not gonna die. I'm gonna be alright...I'm gonna survive this thing' - You *will* survive it.

So, it's all about what's in your head. What's in your mind, *what* you *want* to do. [pause] You know, we have people with *cancer*. It's not like you're alone out there. People have cancer; muscular dystrophy. And there's people who are mentally retarded. You have so many illnesses out there...people are actually *surviving*.

Why?

Because they choose to. Because they *want* to.

[pause] So, you know, it has to come from the person, You know. Don't give up. Just like that.

'Oh...I've got HIV. I'd better jump out of the window.'

It's not like that. [pause] You know...You can still *live*, if you *choose* to.

Joe, 27, New York 1993

For the people that are rejected; that feel rejected; that feel loneliness, that you're HIV: *stop* pitying yourself. There's a lot of people, out there, that have been HIV for *years* and years. They don't tell anybody, but they're wasting away, slowly. Because they feel like they're gonna be [pause] like, labelled. You know...like: 'She was an addict. She was a prostitute' ...But you see...you could've had HIV by having sex [pause] once with somebody. You don't have to go out to anybody. But your man came back. Or, your woman came back. And gave HIV to you.

Now, you got to learn how to *live* with it, you know. The whole idea about HIV is: Don't look where it came from. *Don't* look who to blame for. But learn how to start *living* with it. Now you *got* it, take *care* of yourself. Now you have it, say 'I need to *know* what HIV is. I need to know the symptoms. I need to know what's going to *happen* to me...I need to know how I can get strong. How I can fight this immune system virus; try to knock it down; help me build back up. Try to build up my immune system.

Lucy, 40, New York 1993.

You know, you have to be willing.

Change has to come from within you, regardless of what *anyone* else may say or do.

If you want to change your life, you have to want to change it. I can't change your life. But I can change mine. And I have to accept the things I cannot change. As well as to have the courage to change the things I can.

Howard, 26, New York 1993

Hey, your mind is a very tricky thing, if you don't use it right: if you're feeling sorry, or [like]: 'I'm going to die. I'm going to die!' The next thing you know, you're dying quick. But, if you [realise] you know, that there's an attitude linked with it...[That's where] learning to accept it [HIV] comes. And I'm, right now, eight years with HIV.

I'm just glad I know about this HIV now, before it's too late...I [see] the birds flying around; the dogs walking this way; the cat going through the garbage. And my birthday.

Lucy, 40, New York 1993

I want everyone to know, that this is not *death*. I've invested too much into my life, to let this little simple shit stop me from living...I want to live.