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The agendas of "empowerment" in HIV & AIDS care.

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# The agendas of "empowerment" in HIV & AIDS care

## Abstract

"Empowerment" may be a diffuse and enigmatic concept or process but is gaining a currency within the ideologies of care. The largest group of service users in HIV & AIDS care are gay men and empowerment could be characterised as agency within existing social networks and volunteer organisations through their struggle with "expert systems". Whilst differing discourses of self-help and empowerment are emerging their coexistence may serve different agendas from the *a priori* controlling influences of the unequitable power of professionals.

## Introduction

The 19th century writer and proto-feminist George Sand, who served as a virtual Minister of Propaganda for the 1847 French republican government<sup>1</sup>, wrote

"In works of scientific genius, it is reflection which draws the inner essence out of the simple fact. In humbler imaginative works of art, it is reverie which attires and embellishes the solitary fact. The complexity or simplicity of the work is irrelevant. **The working of the spirit is the same for both.** (my italics) (Sand, 1852: 5).

By quoting Sand's view of a similarity in scientific and artistic processes (a view I bear witness to), I do not wish to imply that this paper is a work of "scientific genius". However, I do wish open a debate about empowerment in HIV & AIDS<sup>2</sup> care<sup>3</sup> by "drawing" out what are the agendas<sup>4</sup> implicit in discourses<sup>5</sup> surrounding self-help and "empowerment" in HIV & AIDS.

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<sup>1</sup>Barry, J. (ed)(1979) George Sand In Her Own Words. London Quartet. pxxxxvi.

<sup>2</sup>HIV & AIDS refers to different yet related phenomena. I argue that the term itself "HIV & AIDS" embodies a debate around causation and the nature of the epidemiological evidence of HIV correlation with AIDS. Terms like "HIV disease" attempt to present "HIV & AIDS" as a unitary phenomenon. The phenomenon of AIDS and HIV transmission are referred to as HIV & AIDS.

<sup>3</sup>In this debate the "field of HIV & AIDS care" is defined as the totality of HIV & AIDS service provision which spans specialist and generalist care provision and will include health promotion and HIV prevention services, associated and support networks which I have in principle joined together purpose of discussion.

<sup>4</sup>The New Collins Dictionary and Thesaurus defines "agenda" as "a schedule or list of items to be attended to, matters to be attended to, at a meeting".

<sup>5</sup>I borrow Grace's definition of "discourse": "discourse is used to refer to primarily language, but including other significations such as images, gestures, which are part of a particular field of activity such as "health promotion". "Discourse" is used instead of "language" because discourse connotes the actively political and

Through a cursory "reflection" upon some of these agendas or "inner essence(-s)", I will aim to develop further understanding of the (not so) solitary fact of empowerment in HIV & AIDS care and how the meanings attributed to empowerment, or "inner essences", may represent more than its "simple fact". Rayah Feldman says empowerment is more "often on the tongues of providers" than recipients, service users, patients, or consumers: its both an "achilles heel" and a "holy grail".

I will begin by a brief description of one early reference to empowerment from Solomon (1976, 1987) and relate some characteristics from her analysis to empowerment discourses in HIV & AIDS care to develop an argument similar to that of Victoria Grace<sup>6</sup> about the concept of **empowerment** as a **professional** or **establishment** response, answer to demands or agenda over increasing control through the construction of "**health consumer**".

This "response" or construction simultaneously positions differing communities as being in **control**, as the initiator or the **operator**<sup>7</sup>, with the professional as the facilitator of what is already is occurring in the community, through using words and their associated meanings such as **enabling** and **empowering**. This serves as a way of distinguishing such differing roles. Grace<sup>8</sup> argues how there exists behind this, at a distance once removed, the professional which are strongly directs and is heavily implicated by the actions which follow.

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strategic role of word and how they are connected to form sentences and construct meaning. This differs from understandings of "language" that imply universal and fixed linguistic structures and meanings for words. An analysis of discourse is concerned with discovering how and under what conditions words and phrases have specific meanings and what can be learnt about politics underpinning the structuring of a particular discourse at a given historical moment." (Grace, 1991, 330)

<sup>6</sup>Grace (1991)

<sup>7</sup>A term I borrow from neuro-linguistic programming, a "new age" methodology linking many fields such as communication theory and Chomskyan linguistics (O'Connor & Seymour 1990).

<sup>8</sup>Grace (1991)

## Origin and emergence of empowerment

What is empowerment ? Is this a virtual phenomenon born out of the artifice of our current governmental rhetoric, posing for us in the "there is no alternative" ideology (or TINA<sup>9</sup>) pervading around care being too expensive.

Recently this is shown in school planning which now seeks to impress financial management or "managing your money" empowerment, or "power over your money" through the national school curriculum, where alternatively sex education within the school curriculum is a "sensitive subject" still for 1996.

A member of the Association of British Industry was quoted on the front page of The Guardian with this empowering comment:

" It is crucially important to let people know that the welfare state is not going to provide everything. Even now an old age pension provides nothing like a decent standard of living. People have got to realise that **care does not come free.**"

(my italics. Donovan & Buckingham, 1996: 1)

Furthermore, could empowerment be a virtual concept, an artifice from arising out of our societal ideology, or is it a tangible phenomenon ? Is it really "out there", or "in there", as a felt experience which can be understood for all the differing human realities there are in addition to the market ?

Victoria Grace<sup>10</sup>, Mai Wann<sup>11</sup>, Paolo Freire<sup>12</sup> and Frankl<sup>13</sup> have researched several of these related concepts such empowerment, self-help, consciencdo and self-transcendence. At a certain

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<sup>9</sup>Recently the Marxist journal "Living Marxism" held a conference titled "Myth of Empowerment". The concept and ideological underpinnings of TINA were heatedly debated.

<sup>10</sup>Grace (1991)

<sup>11</sup>Wann (1995)

<sup>12</sup>Freire (1973)

<sup>13</sup>Frankl (1969)

level there are similarities as they appear to emerge from within "grass roots" action taken by individuals and communities in their often radical efforts to stem poverty, apathy and to reduce such impotence individuals have felt in the face of direct state power or authorities.

Barbara Solomon<sup>14</sup> was one of the authors to first write about empowerment within a social context and in connection with its linguistic relationship to power and powerlessness. Solomon focused on how empowerment emerged within the North American black communities experiences with social work. Solomon's analysis and conceptualisation is useful and relevant in the context of empowerment in HIV & AIDS care because it relates directly to stigmatised groups, which are over represented in those diagnosed with HIV infection.

Solomon describes how helping professions moved away from intrapsychic explanations of human problems around people's psychological and social functioning linking **empowerment** with power, a "bridging" concept, which describes aspects of social relationships such as family, small group, and organisational or community levels arguing how this is complementary to both empowerment and emerging ecological systems approach to human needs or problems.

Solomon characterises ecological frameworks as viewing human needs or problems as the outcomes of dysfunctional "person-environment relationships" where the goals of professional interventions become those of competence, autonomy, self-esteem and relatedness, which must take into account the dynamics of such negative outcomes as oppression and other injustices, thought of as coming from the misuse of power.

Solomon convincingly argues that empowerment is consistent with this 1970s ecological or systems approach to human needs or problems:

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<sup>14</sup>Solomon (1976,1987)

"Empowerment is essentially a method by which helping professions attempt to deal with the **power blocks** experienced by negatively valued individuals and families" (Solomon, 1987: 80)

Empowerment refers to "the reduction in the overriding sense of powerlessness to direct one's own life in the direction of reasonable personal gratification."<sup>15</sup>

Solomon describes how power block can be experienced by members of stigmatised collectives:

"Power blocks are ..... any act, event or condition which disrupts the process whereby individuals develop effective personal and social skills" (Solomon, 1987: 80)

Solomon then draws the distinction between **direct blocks** which are applied forcefully by agents of major social institutions and **indirect blocks** which are incorporated into an individual's developmental experiences as they are mediated by relationships with "significant others". Solomon describes how the experience of direct and indirect power blocks may be seen at primary, secondary and tertiary levels of individual and collective experience.

Perhaps within the 1990's British health and social care "market" whoever may be powerful enough to define human needs may also define the agenda for empowerment. Parsloe and Stevenson (1993) in their focus on the "ideal of empowerment" in social care, also question the tensions inherent in the fundamental principles of our government's "new" community care. For example, needs-led assessment is that which defines the particular agenda:

"In this guidance the term (need) is used as a shorthand for the requirements of individuals to enable them to achieve, maintain or restore an acceptable level of social independence or quality of

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<sup>15</sup>Solomon (1976,1987)

life, as **defined by the particular care agency or authority**"  
(my italics. Manager's Guide to Care Management and  
Assessment in Stevenson & Parsloe, 1993: 7)

Servian<sup>16</sup> analyses empowerment theory and its relationship with individual's power in terms of community care of people with learning difficulties and further argues how the word "empowerment" is a **living** entity and how its meaning is **shaped** by our government's ideological drive to promote the perspective of how life is often better for individuals to meet their own needs.

Servian focuses on the continual redefinition of needed, in the rationing of welfare budgets, as evidence of the official view of empowerment as to access resources. Thus, there will be restrictions on who should be empowered, through a consumer or market process which mediated through "assessments" how **much** and at what **cost** who shall receive it.

### **Empowerment in HIV & AIDS care**

How may empowerment be defined and characterised by people diagnosed with HIV & AIDS and how do services and providers create an environment where people "living with HIV & AIDS" are "empowered" ?

Hopper describes the role of the voluntary sector and how "empowerment" should be:

"the prevention of HIV transmission and the recognition of the rights of people with HIV/AIDS not only to quality services, but to empowerment on an individual and collective level. **Facilitating** this **empowerment** will continue to be a role for voluntary sector in relation to HIV/AIDS (Hopper, 1991:38)

This links empowerment with reducing HIV transmission, but is this referring to some of us as

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<sup>16</sup>Servian (1996)

gay men, or is it referring to the "general" population via fears of risk and disease transmission found most recently in the (known) (un-) reliability of the ELISA test kits from Abbott laboratories for detecting HIV antibodies.

Jeffrey Weeks<sup>17</sup> has shown how UK AIDS volunteer organisations are at the sharp edge of the empowerment in HIV & AIDS care during the 1980s and early 1990s. In one report, ten percent of those surveyed acknowledged their own agency was "empowering" people with HIV/AIDS as a *raison d'être*. Weeks's study is a detailed account of the process of empowerment in voluntary sector work around HIV & AIDS. Thus the altruistic care activism and successful political lobbying for sector funding, as well as in the skilful utilisation of discourses such as "de-gaying"/"re-gaying" to influence national agendas are all part of this "empowerment" process. Cindy Patton<sup>18</sup> notes how the intermittent "de-gaying"/"re-gaying" discourses may be but a background/foregrounding manoeuvre, which Patton after Eve Sedgwick, suggests exactly how science in really does proceed: but not through the competition of the fittest explanatory themes, but through a working out of an appropriate narrative in order to reconcile conflicting schemes and using cultural metaphors.

However, there may be more concern around the "new" marketised health and social care system, as it imposes drastic change on the "old" public sector ethos and provision, which for all of its faults, was at least able to produce a highly motivated and altruistic workforce.

What challenges may lie ahead for the client-led conceptualisation of empowerment within the existing market-led formulations of empowerment and service provision? Service publications may be useful in showing us, and indeed influencing and alerting us through their words, for what may be to come.

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<sup>17</sup>Weeks (1996,1994,1993)

<sup>18</sup>Patton, C. (1990) *Inventing AIDS*. London: Routledge. p. 152, note 31.



For example in the field of HIV & AIDS health promotion, we, are told by the new HIV prevention journal Agenda how our efforts have become "abysmally passive". According to Agenda, which is fortunately titled for this afternoon's seminar with its subtitle too, of "Influencing HIV Policies and Practice", what is needed is a new "Strategy for success" in order to respond to governmental "re-targeting" or "down-sizing" (or cutting) of HIV prevention services. This makes sense as the government says "given that there is no cure for HIV or AIDS, the Government remains committed to health promotion as the only way to prevent HIV from spreading (DOH, 1995; 3).

This new "Evolving Strategy of HIV Health Promotion" is welcomed by services as it catches up with the evolving epidemiology. But as Edward King reveals<sup>19</sup> the way the funding cake was cut deliberately limited the lack of resourcing for gay men.

I argue that Agenda's "**agenda**" for their "Strategy for success" should be seen by reflection upon their present editorial:

"Strategy for success

.... we've changed as a society and as "vulnerable groups". Individualism is in, politics is out. Looking good, having an excellent time and shopping is what we've turned into.

HIV prevention will have to be something different, something that fits with how we are, that fits with our late 90's lottery mad, stakeholding Tesco Club Card culture." (Pickstone, 1996: 3)

Victoria Grace<sup>20</sup> argues how the promise of empowerment cannot be fulfilled by health

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<sup>19</sup>King (1993).

<sup>20</sup>Grace (1991)

promotion, as its appealing construction of the individual subject as a "health consumer" closely accords and ultimately is corrupted by the power strategies in our society with its thrusting consumer capitalism. I would argue that this reflects Solomon's framework: health promotion can be conceptualised as it currently is "constructed" as a direct or indirect block to the reality or hope of empowerment.

Within the self-help HIV & AIDS literature there is a **spectrum of empowering discourses** which embody different viewpoints, perspectives and experiences of being unwell, staying well and living with the virus:

"Falling in love with AIDS. The disease is part of us, as positive people. When we fall in love ... We have to ask them to see something in us which is beyond the consequences of AIDS which was there before." (Holmes, 1995: 2-3)

Publications such as Body Positive perform a resource function in the development supportive networks, informing on welfare benefits and services as well as reflecting people's perspectives:

"What I want ... is a media campaign ..... on how I want to be treated as a person with HIV in the employment market.

I do not want to be overwhelmed by great advice from people in the HIV sector, telling me what to do and how to live my life .....

**Work is life. And I want to live."**  
(my italics. Koble, 1995: 3)

There are a multitude of possibilities within the discourse which may function to shape or shatter expectations, guide the "health consumer" and sift the multiple complexities within the discourses of **options** or **choices**:

"These results have **very important** implications for how people with HIV and AIDS will be treated in the future.....

The findings from Delta **should dictate** that from now on.....

**but....not been able to positively determine** that there will be **any** benefit ..... in increased survival." (my italics. Poppa, 1995: 1-2)

The sheer multitude of discourses whilst being supportive of a greater spectrum of **positions** surrounding HIV & AIDS care and treatments and choices reflect imperatives such as obtaining prescription and non-prescription drugs which some treatment activist organisations such as ACTUP early campaigned for "compassionate" release before research trials eg. Zidovudine (AZT). Today it is protease inhibitors:

Getting protease inhibitors.  
Indinavir, the **potent** protease inhibitor .... is to become available to people with HIV in the UK .... at least six months **ahead** of being granted a formal licence." (my italics. Alcorn, 1996: 1)

However, such HIV & AIDS self-help literature in its totality may function to lobby, campaign and disseminate other unpopular or what has become known as **dissident** perspectives:

"Absurd Convictions

There's the scent of blood in the air. The word is out - we could consider criminalising the transmission of HIV ....

Fear of HIV requires ignorance. Would fear thrive if it was generally known that there are thousands of recorded "AIDS" cases without "HIV", and thousands and thousands of "HIV" without "AIDS"....." (my italics.  
Christie, 1995: 4-5)

The spectrum of biomedical, alternative and dissident constructs about the virus and "AIDS causation" can be found in the contrasting of perspectives between different publications: the orthodox biomedical construct of the "slippery slope" phenomenon of **HIV=AIDS=DEATH**<sup>21</sup>

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<sup>21</sup>after Cindy Patton and ACT UP.

may be compared to the alternative theorists and practitioners in the Equilibrium journal or the "pro-life" and "new age-y" views of others such as Postively Healthy.

Going even further along this spectrum there are even more discourses which question the orthodox medical belief in HIV causation in AIDS, for example that of the UK journal **Continuum**. All these discourses are backed up with own position specialists eg. Gallo, Montagnier, Fauci, Sonnabend, Root-Bernstein, and Duesberg.

That such a multiplicity of seemingly mutually exclusive discourses and in their respective agencies they thrive, not just as an artefact of the "market" or "consumer choice", although I have to argue that such factors are important. That they may thrive is may be due to how they reflect deeply felt needs to make and re-make meanings from **individual** or **collective** experiences of direct and indirect power blocks which are professionally mediated within HIV & AIDS care.

The AIDS "dissidence" literature may make for interested or compelling reading, if only because it may serve as a kind of prism, one which splits **some** people's orthodox views or assumptions about the "virus". Celia Farber, a New York AIDS dissident who writes for SPIN magazine, says that what defines your "**take**" on AIDS is what has informed your being from when you are young; thus she identifies one's **position** in the dominant political discourses as vitally important in constructing one's perspective and viewpoint and ultimately one's beliefs around HIV & AIDS, the "virus" and the "epidemic":

"its... your relation to authority, your political views on what role should government play" (Farber, 1996: 10)

When common meanings of the orthodox biomedical constructs surrounding HIV & AIDS are questioned, one feels uneasy, as other's empowerment is questioning and de-constructing

other's realities.

For for those of us working at the practitioner interface in HIV & AIDS, the community, the hospital, the clinic or prevention services and the volunteer organisation, the language of what may be "war" slogans can never be far from our consciousness - "**Gay Men (are) Fighting AIDS**", "**HIV = AIDS = DEATH**", "**progression and non-progression**", "**long-term survivors**" -these agendas can they serve to reflect a variety of agends some about causation of AIDS, others more about gay or treatment activism. However, subconscious beliefs over who is to live and who is to die here appear both profound but problematic.

Ian Young <sup>22</sup> has constructed HIV positivity as a modern day "bone pointing" phenomenon which marks you out like that of the tradition in Aboriginal peoples. Others may find this view an outrageous concept, a dangerous myth, and a fiction. Whatever it is, people have a right to believe, like religion or the flat earth beliefs.

Carers experiences with the community or institutionalised care of people with HIV & AIDS may also call into question medical orthodoxies and power practice. Nurses are entrusted with the **delivery** of medical decisions and so constitute a conduit for subversion, empowerment or

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<sup>22</sup>Young (1993)

otherwise although current ideology appears to be eroding the trust. Well into the epidemic

nurses have challenged the view of passive terminality in AIDS:

"I was a staff nurse in intensive care back in 1982, seeing people with AIDS at the end of their lives, on ventilators.

I found myself being an advocate, pushing to get everything done: pushing to get that Swan-Ganz<sup>23</sup> line in, pushing to get that airway in, and pushing to get that patient intubated, because maybe, you know .....

this was a person at the end of the machine and this person deserved to be given the chance to live

I locked horns a lot with both nursing and medical colleagues."  
(Hirschorn, quoted in Bennett, 1987: 1153)

Again, such words speak of advocacy, of confronting (medical) power and decision-making and of the comparatively powerless (the nurse) taking power or becoming powerful on behalf of and to further the interests of, those having no voice:

"I find myself trying to intervene and not let physicians .....

For example, we had an episode with physicians meeting patients in the ER (Emergency Room) with their first episode of PCP

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<sup>23</sup>Swan Ganz is an intravenous line inserted to measure the force of contraction of one's heart.

(Pneumocystis carinii pneumonia).

The physicians were suggesting that those patients make themselves no-codes<sup>24</sup>. One of the nurses called me down and said, "You'd better get down here quick!"

Not resuscitating people with AIDS almost became a standard of care because the docs didn't want to spend their time." (Gallager, quoted in Bennett, 1987: 1153)

"We're not going to put anyone with AIDS in the ICU (Intensive Care Unit)." But the thought that it could slip by is terrifying.

That patient survived, but he wouldn't have, had he not been intubated for a few days. We are in the position where we have to prevent that sort of thing." (Gallager, quoted in Bennett, 1987: 1153)

"My concern is that people are being told at the emergency room - when they present for the first time or with their first OI (opportunistic infection) - that most people die of AIDS. They are told that chances of surviving if you go to the ICU are whatever and..... it (critical care) will just prolong your dying." (Gallagher, quoted in Bennett, 1987: 1152)

There may be other assumptions around having the virus. The dissidence literature or debate scatters some additional fragments of meaning as there is always the potential to learn more from our own underlying or hidden assumptions about HIV & AIDS.

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<sup>24</sup>"No-code" means do not resuscitate order declared by the "patient" on hospital admission. In the event of heart or respiratory failure, no efforts would be made to "artificially" prolong life.

Christine Maggiore<sup>25</sup> talks about the unity in which we of the gay community which have been witness to and suggests that this can be used by orthodox medicine. Although HIV & AIDS has brought gay people together, our suffering is on view for the attention of the world. Maggiore suggests that it is hard enough for people who are gay to stand up and fight for equal rights:

"I'm Gay, and you know, I'm going to fight for my rights, and the rights of people like me".

To take away that rallying point would be to take away a lot.

And then there's the overwhelming amount of losses, we have seen so many die, its hard to get past the pain and ask hard questions such as,

"God, did we jump too soon at the first thing that seemed like it made sense to us".

And the deaths of all our friends, all our lovers, all the people we hung out with - were all of those deaths in vain ?

That's a very hard question for us to ask. It's easier to say:

**"Fuck you, with your stupid information !  
Go away ! Leave me alone !"**

(Maggiore, 1995: 8-13)

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<sup>25</sup>Maggiore (1995).



Yet another issue which fuels the disocurse is suggested by Maggiore as the "war" mentality, the so-called "**war on AIDS**":

"Before the service people left for the Gulf War, they were given these experimental vaccines.

The governments didn't mention what they were doing, until the people came back and had kids that were without arms, like Thalidomide babies.

But what allowed them to do that was the idea that "there's a war on" !

That justifies all these preposterous behaviours; the oversights of gaping holes in the whole theory; and the **erosion of civil rights and privacy**. "There's a war going on !"

**It's like there's martial law in the medical industry."**  
(Maggiore, 1995: 12-13)

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