Let's stop talking about AIDS

by Simon Watney

Most readers will be familiar with the history of how the Acquired Immune Deficiency Syndrome was first identified in the United States in 1981[1]. Doctors in New York and Los Angeles had independently reported significant clusters of cases of two previously very rare medical conditions—pneumocystis carinii pneumonia (PCP), and a form of cancer known as Kaposi's sarcoma (KS). The only connection between these, and a number of other rare diseases being reported amongst otherwise healthy young gay men, was their known association with damage to the body's immunological defenses.

Because these clusters were first identified among gay men, they were at first collectively described as Gay Related Immune Deficiency (GRID). It was eventually recognised (and not without considerable resistance on the part of some doctors and epidemologists) that the underlying causes of these clusters of rare diseases was not specific to gay men, especially after it was discovered that the unknown agent (or agents) responsible for them could be transmitted via blood transfusions. Thus, in 1982, the Center for Disease Control (CDC) in Atlanta, Georgia, officially classified the condition as Acquired Immune Deficiency Syndrome, by which name it is still widely described.

The Human Immunodeficiency Virus (HIV), which is responsible for AIDS, was not isolated until 1983, and not made public until the following year. In all of this it is important to remember that doctors, and members of the gay community, were working *backwards* in a *detective* manner, in order to establish the agent responsible for AIDS, and to understand its possible modes of transmission in order to protect people. Thus it was that Michael Callen and Richard Berkowitz wrote their groundbreaking pamphlet *How to Have Sex in an Epidemic*, with a preface by Dr. Joseph Sonnabend, in 1983, on the assumption that some sexually transmitted factor was responsible for many if not all cases of AIDS. That was the originating moment of what we all now know as Safer Sex. Nonetheless, even now in 1988, the distinction between HIV and AIDS is still far from universally understood, and AIDS is widely regarded as if it were a single *disease*, rather than a *syndrome*, which refers to a huge range of conditions which may emerge in the wake of HIV infection, and damage to the body's immunological defenses.

> The easiest and most logical way forward would surely be to gradually abandon the category of ARC and AIDS altogether and to encourage the adoption of a simpler — and more accurate distinction between HIV infection and HIV disease.

AIDS is NOT a single condition

Hence the need to repeat that AIDS is *not* a single condition, and that different people diagnosed with AIDS will not therefore necessarily share any medical or clinical experience. AIDS can be experienced in a wide variety of sequences and combinations of what are known as "opportunistic" conditions—conditions which have taken the "opportunity" (horrible word) of damage caused by HIV. It should also be stressed that most of the conditions which may lead to an AIDS diagnosis are present in *all* of us, but are held in check by our immune system.

It is this set of relatively straightforward facts which is difficult to communicate to many people because of the way in which AIDS was first identified and classified back in 1982. Many of the most basic misunderstandings about AIDS stem from a failure by journalists and others to appreciate the sheer diversity of medical experience, and the complexity of issues raised by a syndrome. To describe AIDS as if it were a single disease is an easy option, but it obscures almost all the real issues faced by individuals with AIDS, and has led to any number of misleading assumptions and ill-informed beliefs about almost every aspect of the epidemic. For example, many people still talk about "catching AIDS, and the belief that there is an "AIDS test" remains unfortunately widespread.

Strong reasons to bypass AIDS

There are thus strong reasons why we should consider following the example of doctors who have bypassed the notion of AIDS, just as AIDS bypassed the earlier classification of GRID. They talk of *HIV infection*, referring to the specific and limited modes of transmission of the virus; and *HIV disease*, referring to the disease of the immune system itself and the wide spectrum of subsequent medical conditions which may arise in the wake of HIV infection.

There is another compelling reason why we should consider this as a significant advance. As knowledge concerning the effects of HIV grew in the 1980's it became cle
that a large number of people wi
HIV were becoming seriously i
though they did not have illness
which are officially classified
AIDS. The revision and enlarg
ment of the diagnostic category
AIDS by the CDC in August 19
has not really improved the situ
tion of all those people who still fi
themselves diagnosed as peop
with AIDS Related Complex (AR
sometimes known as AIDS Relat
Conditions.

A diagnosis of ARC is in so
ways even more difficult for ma
individuals to live with than a dia
nosis of either HIV infection,
AIDS. ARC is widely seen as an "
between" condition, half-way
tween HIV and AIDS. This only
courages the use of absurd ter
like "full-blown AIDS" to refer
people with symptoms of the sy
drome, and implies that peop
with ARC have "half" or "ser
blown" AIDS!

A simpler, more accurate distinction

It is clear that nobody set out
deliberately construct this Chin
Box of medical categories, with
the confusion and misunderstan
ing which they tend to reinfor
The easiest and most logical w
forward would surely be
gradually abandon the categor
of ARC and AIDS together, and
encourage the adoption of
simpler—and more accurate—
tinction, between HIV infection a
HIV disease. In this way large nu
bers of people would be spared
totally unnecessary stress involv
in an ARC diagnosis, which i
cruel and sadistic category w
which nobody should in future
obliged to identify their experie
of HIV disease. This would a
have the advantage of undermin
much of the demonizing myth
ogy surrounding the present cl
sification of AIDS. It would a
make the task of HIV education
easier, and by making the epide
more comprehensible to mo
people, might help in the cruc
task of preventing further inf
tions, and improving the gene
quality of life by everyone affect
the consequences of HIV infecti
and HIV disease.

[1] *The Search for the Virus* by Steve Con
and Sharon Kingman (Penguin, 19
provides the clearest available acco
of this history.

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Education Group of Britain's T
rence Higgins Trust.**

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