

**HARD TO
REACH
OR OUT OF
REACH**

**AN EVALUATION OF AN INNOVATIVE MODEL
OF HIV OUTREACH HEALTH EDUCATION**

Tim Rhodes, Janet Holland and Richard Hartnell

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CHAPTER ONE

INTRODUCTION

The evaluation of CLASH was conducted as part of a three year Department of Health (DoH) funded study investigating outreach health education as a means of preventing HIV infection among hard-to-reach populations. The research project had three objectives: to review models of HIV outreach health education in Europe and the United States (US) (Rhodes *et al.*, 1990; 1991a); to conduct a survey of HIV outreach interventions in the United Kingdom (Hartnoll *et al.*, 1990; Rhodes *et al.*, 1991b); and to evaluate an innovative model of outreach health education in central London - Central London Action on Street Health (CLASH).¹ This book describes the evaluation. We have provided a summary report outlining the main findings from the research project as a whole elsewhere (Rhodes *et al.*, 1991c).

HIV prevention and outreach intervention

There are certain populations who are unlikely to be effectively reached by conventional HIV prevention strategies of health education, health promotion, counselling, sexually transmitted disease (STD) services, and drug advice agencies. These include hard-to-reach populations within the traditionally more difficult to access groups of injecting drug users, women and men working in the sex industries, homeless or transient young people, and their sexual partners. For example, it has been estimated that half of Britain's drug users are not in contact with treatment or helping agencies (Hartnoll and Power, 1989; Drug Indicators Project, 1989). It has also been found that those not in contact with helping agencies are more likely to be engaging in HIV transmission behaviours (Power *et al.*, 1988; Stimson *et al.*, 1988).

Although the hard-to-reach are a relatively small proportion of the total population, they are likely to be important in the transmission dynamics of HIV (Des Jarlais and Friedman, 1987; Padian, 1988). This arises both from the prevalence and frequency of HIV transmission behaviours which occur among them (Coleman and Curtis, 1989) and from their

high level of mobility and interchange, occurring across different social networks and geographical areas (McDermott, 1988).

In response, there has been an increasing interest in the development and implementation of 'innovative' HIV prevention programmes, often based outside formal health service settings, with an emphasis on 'community-oriented' and 'user-friendly' approaches. Over the last two or three years HIV outreach intervention strategies have proliferated. Outreach has quickly come to be viewed as an essential, if not central, component of wider HIV prevention initiatives. But despite the sense of urgency which has surrounded the emergence of HIV outreach in the United Kingdom, a lack of descriptive and evaluative material remains, and little is known about the nature and comparative efficacy of differing interventions. We hope that this and previous reports will redress some of this imbalance by providing a national and international context for the interpretation of findings and by facilitating the design and implementation of future interventions.

Definitions of HIV outreach health education

For the purposes of our research, we have defined HIV related outreach health education as follows (Rhodes *et al.*, 1991c):

“A community oriented activity with the overall aim of facilitating improvement in health and reduction in the risk of HIV transmission for individuals and groups from particular populations who are not effectively reached by existing services or through traditional health education channels”.

The means of achieving these aims are based on identifying gaps in existing service provision and providing effective health education and services to populations within the community not yet adequately covered. HIV related outreach can thus be directed towards two target groups:

- i. individuals or groups considered vulnerable to HIV infection as a result of engaging in particular transmission behaviours, for example drug injectors and sex industry workers;
- ii. populations or communities not defined primarily in terms of specific transmission behaviours but thought to be at increased risk due to the failure of communication of appropriate health education messages through existing channels, for example young people and specific ethnic minority groups.

Within this broad definition of outreach, there are two sub-divisions: detached and peripatetic outreach.

Detached work is undertaken outside any agency setting, for example work undertaken on the streets, station concourses, in pubs and cafes. This may aim either to effect risk reduction change 'directly' (*in situ*) in the community, or to facilitate change 'indirectly' by attracting individuals into existing treatment and helping services.

Peripatetic work focuses on organisations rather than on individuals, for example work undertaken in prisons, syringe exchanges, hostels and youth clubs. Peripatetic outreach places emphasis on broadening the range of people who are reached with health education messages, expanding their knowledge about available services, and training other workers and staff.

Outreach intervention and health promotion

The increased interest in community-oriented and community based approaches to health education and service provision over the last decade has led to challenges to conventional models of disease prevention associated with bio-medical understandings of health and illness (Doyle, 1979; Brown and Margo, 1979; Crawford, 1977, 1980; McKeown, 1979). Historically rooted within medical and epidemiological traditions, these models emphasise the belief that disease can be prevented by identifying and removing a causative agent of disease (Jewson, 1975; Allsop, 1984). This has often meant regarding the individual - and the body - as the focus for medicalised scrutiny in the search for specific aetiologies of disease in order to prevent their onset, if not to provide their management or 'cure' (Armstrong, 1983; Foucault, 1973).

In the light of these ideas, prevention has often been defined and organised in a tri-partite fashion, and strategies of health education have aimed to perform three complementary functions (Tones *et al.*, 1990). At the level of primary prevention, health education functions to persuade people to adopt behaviours thought to reduce the likelihood of disease, its related harm, and to encourage utilisation of existing services ('health behaviour', 'harm reduction' and 'help-seeking behaviour'). At the level of secondary prevention, health education functions to persuade individuals to practise self-care and to comply with medical recommendation and treatment. At the level of tertiary prevention, health education functions to persuade individuals to comply

with medical treatment and to adjust to the limitations of lifestyle imposed by the presence of illness.

Approaches to the prevention of HIV infection have recently made explicit the problems associated with such rigid conceptions of prevention, health education and health and illness. Conventional medicine has been unable to find automatic 'cures' or 'magic bullets', and both the production of HIV disease and compliance with risk reduction practices have been shown to relate more to social, cultural and environmental factors than simply to bio-medical ones. In this way, the practice of HIV prevention has been located in wider discussions about public health, 'public good' and individual liberties (Porter, 1986; Porter and Porter, 1988), and about social inequalities on aspects of gender, sexuality and race (Watney, 1988a; 1988b; Treichler, 1987; Patton, 1988; Holland *et al.*, 1990). Approaches to health education which focus purely on the individual are therefore less appropriate than approaches which aim to encompass ideas of community, social or environmental change.

The commitment to developing community-based responses to intervention has developed both from within and outside the National Health Service (NHS). From within the NHS, these moves have seen increased emphasis on community development approaches to health, focusing on community participation and consumer health needs. The establishment of a Professional and Community Development Division within the Health Education Authority (HEA) in 1988 and the passing of the Community Care Act in 1990 are both moves in this direction (Webster, 1991; Smithies and Webster, 1991). As a result, there has been a narrowing of divisions between 'external' approaches to community development (for example, NHS initiated) and 'internal' approaches (initiated within communities themselves), and each have begun to occupy the same organisational space. Community health and self-help initiatives arising from within the community have increasingly gained funding from the statutory sector rather than from the charity and voluntary sector, and have begun to view the aims of their work - such as community participation and the redressing of health inequalities - in similar terms to wider agendas such as those of the World Health Organisation (National Community Health Resource, 1989).

This commitment to the development of community-based approaches to health promotion has been accompanied by a proliferation of attempts to categorise the diversity of health education practice (Draper *et al.*, 1980; French and Adams, 1986; Homans and Aggleton, 1988; Tones, Tilford and Robinson, 1990; Tones, 1981; Tuckett, 1979). In general, four models have been distinguished: the 'information-giving' or

'preventive' model; the 'self-empowerment' model; the 'community-action' model; and the 'radical-political' or 'socially transformatory' model. In an attempt to understand the role of HIV related outreach health education in the wider context of health education practice, we draw on some of our previous work, and briefly go on to describe each of these health education models in turn, before outlining the apparent theoretical value of outreach over more conventional health education approaches.

Information-giving models

Information-giving models of health education employ bio-medical understandings of health and illness and are rooted in the traditional 'preventive' approach. The model gives priority to the provision of information based on the belief that there are causal links between individuals receiving health information messages and modifying their health behaviour. This model is epitomised by the classic K-A-B (knowledge-attitudes-behaviour) approach to health education and presumes the translation of information to behavioural modification to be a relatively unproblematic and rational process.

In relation to the prevention of HIV related harm and problematic drug use, the British Government's main preventive response - the use of the mass media and advertising - is clearly rooted in this approach. That the translation of information into behavioural modification is indeed a problematic process has been borne out by the diversity of responses (many negative) to the various campaigns (Research Bureau Limited, 1989; Watney, 1988c; Rhodes and Shaughnessy, 1990; Power, 1989).

Self-empowerment models

Models of self-empowerment, which are also individualistic in orientation, are based on ideas of 'informed choice', and unlike information-giving approaches, aim to "improve health by developing people's ability to control their health status within their environmental circumstances" (French and Adams, 1986). They emphasise the facilitation of personal growth, self-empowerment and self-assertiveness.

This approach to health education and behaviour change is employed in many HIV counselling centres in the UK (Silverman, 1990), but can also be found in community-based interventions. The 'bleach and teach' campaign organised by the Mid City Consortium to Combat AIDS in San Francisco aims to provide drug injectors with the means (bleach) to enable rational choices to be made about injecting behaviour in situations which might otherwise have impeded the ability to make such choices

(Feldman and Biernacki, 1988). The establishment of the syringe exchange as a user-friendly, community based service over the past three years in the UK, has also endorsed the principles of self-empowerment by providing individuals with the means to inject safely.

Self-empowerment initiatives like syringe exchange, however, may be only partially effective, helping individuals to cope with rather than to change their circumstances (Pearson, 1973), and are generally unable to meet the needs for wider community or collective change. There are, for example, many instances when equipment sharing may be both socially desired and socially acceptable - when injecting equipment or exchanges are unavailable, when being initiated into injecting, when intoxicated, when sharing with particular partners, when in particular settings and so on (Haw, 1985; Friedman *et al.*, 1986; Feldman and Biernacki, 1988). These problems are further compounded by the limited success which syringe exchanges have had in reaching hard-to-reach drug injectors and those most vulnerable to infection, and the considerable difficulties experienced in maintaining contact with these clients over time (Stimson *et al.*, 1988). In a similar fashion, low threshold methadone programmes, and some treatment-oriented outreach interventions (for example, the New Jersey Coupon Program [Jackson *et al.*, 1987]) may also be limited in scope. Although they can be seen as empowering in the sense of enabling individuals to use drugs more safely and to achieve a more stable level of social functioning, they may also minimise client autonomy by encouraging a dependency on treatment methods themselves. It is clear that there is often a need to extend beyond the boundaries of self-empowerment and individually focused interventions in order to acknowledge the social and cultural constraints on health behaviour and to instrument change socially in the community.

Community-action models

In contrast to models of self-empowerment, community-action models of health education recognise the need to account for social and community 'norms' and 'values' when attempting to modify health behaviour. They therefore aim "to enhance health by bringing about community change through collective action" (Aggleton, 1989), emphasising "self-organisation and mutual assistance" (Beattie, 1991).

The Chicago AIDS Community Outreach Intervention Project is perhaps the best established model of community-action outreach intervention. The model is founded on an established tradition of developing innovative community-based programmes designed to intervene and contain local

outbreaks of heroin use and addiction (Hughes and Crawford, 1972). Based on a multi-method approach which combines the principles of medical epidemiology with those of community ethnography (Wiebel, 1988; 1991), the model has key factors which facilitate change collectively in target communities. The use of 'indigenous' outreach workers, who function as 'AIDS Prevention Advocates', facilitates access and communication with target groups. The use of community ethnographic methods, and of ethnographers as outreach workers, helps to identify community norms and values attached to certain HIV relevant behaviours, and assists in the design and formulation of appropriate health education responses and recommendations. Finally, the encouragement of clients to become AIDS Prevention Advocates themselves enhances feelings of social responsibility among their peers and stimulates a collective response to HIV prevention.

There are many other examples of community-action HIV prevention and outreach programmes (Rhodes *et al.*, 1991a), and such initiatives are well established in gay communities (Veenker, 1990). Some of the latter have remained completely community-based and have refused government subsidies (for example, Aides in France, the Gay Men's Health Crisis and the Stop AIDS Project in the USA), others have accepted subsidies and formed more general non-government organisations (for example, AIDS Hilfe Verein in Germany, AIDS Hilfe Schweiz in Switzerland and the Terrence Higgins Trust in the UK). Without the same pre-existing social and organisational networks, the extent to which community organisation has occurred among drug using communities has been limited. Self-help groups like ADAPT in New York (where impetus for organisation initially came from outside the drug using community), the Junkiebonden in the Netherlands (Friedman *et al.*, 1988), and the Deutsche AIDS Hilfe (Narimani, 1991) are, however, fast gaining momentum.

Radical-political models

Moving beyond community-action models, radical-political or socially transformatory models aim to bring about "far reaching social change throughout society" (Aggleton, 1989). In recognising the social and regulatory constraints on achieving harm reduction behaviour, these models aim to achieve social, fiscal, legislative or environmental change by triggering collective political action.

Approaches such as this have been made in the Netherlands by Red Thread (Verbeek and Van der Zijden, 1988) and in the United States by COYOTE (Call Off Your Old Tired Ethics) among women working as

prostitutes (Delacoste and Alexander, 1988). Each of these groups view sex workers as having little power or opportunity to create safer working conditions and to promote safer sex within them because of the contradictions which exist between restrictive and punitive official and legal policy on the one hand, and social reality (the demand for commercial sex) on the other (Biersteker, 1990). Both groups have been involved in developing outreach programmes which take account of these situations: for example, the operation of 'safe houses' in Amsterdam (AIDSCOM, 1989), and 'Cal-PEP' in association with AWARE (Association for Women's AIDS Research and Education) in San Francisco (Cohen *et al.*, 1988). Similarly, the activist organisation ACT-UP has been involved in politically oriented interventionist strategies among gay men and drug users, and was instrumental in setting up the first syringe exchange in New York despite laws outlawing its existence (Sorge, 1991; Gillman, 1989).

Prescription to participation and the place of outreach

Using a framework which characterises prevention policies in terms of the extent to which they are imposed from above by institutions of authority or negotiated from within the affected communities concerned, Beattie and others have demonstrated how 'bottom-up' and 'top-down' health interventions often come to be polarised to varying extents at either ends of the authority-negotiation spectrum (Beattie, 1986; 1991; Hardy, 1981). Bottom-up interventions tend to start with the health priorities of communities and involve them as active participants in the process of education, prevention and change, and have been shown to have most in common with health education models of social and community change, such as community-action and radical-political models. Top-down interventions tend to reflect the issues and goals defined as important by health educators and policy makers, and have most in common with 'preventive' models of health education such as information-giving, and to a lesser degree, self-empowerment models. In this general sense, interventions which 'come from above' may be seen as impositions of policy and as inappropriate - sometimes even irrelevant - to the 'people below'. The above review of health education practice indicates that the possibilities for the focus (who) and mode (how) of intervention are poised between those which invite individualism, authoritarianism and prescription on the one hand and those which invite collectivism, negotiation and participation on the other.

These contradictory positions have often become embedded in approaches to health education themselves. The increased interest in community development has encouraged a convergence of approaches between those emerging from within communities themselves and those developed from outside communities by the statutory sector, local and central government and 'authority'. Whilst on one level this has meant an element of intersectoral collaboration, it has also brought into conflict many deep-seated, opposing and competing viewpoints from the variety of theoretical positions involved. The emergence and subsequent decline of the HEA's Professional and Community Development Division provides an example: not two years after it was established, the Division was disbanded, its potential contribution to achieving what could be termed 'community development' effectively controlled and minimised, and restrictions enforced on the publication of independent evaluation findings of its community development strategy (Smithies and Webster, 1991; Webster, 1991).

'Outreach' (as defined above), although often conforming to the principles of self-empowerment as opposed to community-action, can be seen historically to have more in common with bottom-up approaches to health than with top-down approaches (Rhodes and Hartnoll, 1991). Outreach thus contrasts sharply with conventional modes of health education which remain the dominant paradigms for HIV education and prevention (Homans and Aggleton, 1988; Friedman *et al.*, 1990). It has as one of its fundamental aims to identify, reach and provide services according to clients' expressed needs, where existing and more conventional health education approaches appear either inappropriate or irrelevant. In even its most conventional forms, outreach accepts the need for context specific health education, active participation on the part of the client, and recognises that accurate information alone may do little to modify behaviour (Gatherer *et al.*, 1987). In doing so, outreach aims to place health education in the context of individuals' social environments and in the context of social and health inequalities, aiming to explicitly involve clients and communities in the implementation of service responses to ensure that they are appropriate to a range of client and community needs.

Outreach has historically evolved from a range of community-based responses including philanthropy, self-help, social and political reform and community development for health. But like the historical development of community development itself (Webster, 1991), approaches to HIV related outreach are increasingly emerging from a combination of service perspectives, including combined top-down and

bottom-up responses. In the United States for example, interventions operating from a combination of perspectives including community work, self-help, ethnography, epidemiological research and public health intervention are not unusual and may actually be the norm (Rhodes *et al.*, 1991b; Des Jarlais, 1989). In the United Kingdom, most HIV outreach projects remain situated in the voluntary sector (66 per cent in a recent survey, Hartnoll *et al.*, 1990), but projects are increasingly being established within statutory sectors, employing a mix of 'community' and 'professional' responses.

The increased intersectoral collaboration in relation to outreach work - or perhaps the increased involvement from established and 'professional' quarters about HIV-related outreach work - although reflecting wider trends of increased interest in community development as a whole, has its own unique sense of urgency and vociferousness. These moves may be significant in that the contradictory elements embodied in community development may be imported into the specific context of new outreach initiatives, but it may also suggest the potential for 'outreach' to become employed as an 'innovative' institutionalised response to community based HIV prevention.

Evaluation of Central London Action on Street Health (CLASH)

The evaluation of CLASH concentrated on the feasibility and effectiveness of project management functioning and of outreach service delivery. A summary of the evaluation findings, conclusions and recommendations can be found in Appendix A.

This book is divided into eight chapters, which need not be read sequentially. The aims and objectives of the evaluation, the evaluation methods used, and the main problems encountered in their use, are discussed in Chapter Two. The following chapter outlines the historical development of CLASH and the evolution and implementation of project aims and objectives. Findings concerned with the feasibility and effectiveness of the project's management structure and functioning are presented in Chapter Four and discussed and evaluated in Chapter Five, while findings relating to the project's detached outreach work, service delivery and client contact are presented in Chapter Six and discussed and evaluated in Chapter Seven. Chapters Four and Five, and Chapters Six and Seven in particular may be read as separate units in accordance with readers' specific areas of interest, although it should be stressed that issues of management and of service delivery are best

viewed as inseparable. Some repetition between the main chapters is inevitable, given that the same information is relevant to history, practice and organisational structure, but an attempt has been made to minimise this by referring the reader to other relevant sections of the study. Finally, Chapter Eight draws the overall conclusions from the study and discusses their implications for the development of future outreach policy and practice.