

Moved to Act

What can we learn from HIV social movement communication?

‘One thing I have learnt is that when we meet it brings peace into my life. When I am at home, sometimes I think of many things which are not good for me, but when we come for a support group meeting it relaxes my mind. We talk about our daily problems and it really brings peace to me. Even when I go back home I feel good.’

| member of ICW, Namibia¹

Social movements have generated interest in development circles recently as relatively independent expressions of civil society, mobilising people to set their own development priorities and agendas in a range of developing and developed countries. Social movements have addressed issues as diverse as land reform, water privatisation, neo-liberal trade policies, the rights of women and indigenous peoples, and access to HIV antiretroviral treatment.

In the case of HIV and AIDS, independent initiative among civil society has been a key component in successful responses. Social movements of people living with HIV and AIDS, gay men, women, sex workers and people who inject drugs have developed a variety of innovative institutions and responses to HIV and AIDS in different settings, and organised to counter stigma and discrimination in institutions and law.

Social movements and their communication dynamics have much to teach us about:

- what motivates social change and the importance of meanings and values
- the use of novel communication approaches that are culturally grounded
- the limits of the processes and institutions of politics and governance.

What are social movements?

Social movements have been defined as **collective enterprises seeking to establish a new order of life**²

.... and as **interactive networks of people who have shared beliefs and a sense of solidarity, and who come together to take part in collective action to challenge the status quo.**³

.. and as **forms of collective action with a high degree of popular participation, which use non-institutional channels and which formulate their demands while simultaneously finding forms of action to express them.**⁴

Social movements share a range of characteristics: they tend to confront elites, authorities and dominant institutions; they often involve a transformation in everyday habits and the meanings attached to certain ways of living; and are mobilised by ‘culturally resonant, action oriented symbols’.⁵ They tend to be loosely organised with a low degree of institutionalisation, and are interesting more for the way they engage people in processes of mobilisation and social change, than any particular organisational form.⁶

Social movements tend to eschew the usual channels of formal political parties and the ritual of elections, and this separates them from more traditional political campaigns that may also have social change and collective action as their aim. In practice, such engagement with formal political processes by movements varies. At the same time however, more formalised ‘Social Movement Organisations’ may develop, which draw on the more loosely organised broad movement around an issue. Such organisations attempt to be a focal point for particular demands and connect the movement into formal political processes, which raises questions about representation and accountability to the movement as a whole.⁷

What can we learn from social movements?

Motivating change

Social movements often animate social change in ways that formal, external development initiatives struggle to. By bringing people together around shared experiences and promoting a collective recognition of issues and problems that have been neglected, social movements often give people a sense of belonging and an impetus to mobilise for change. The process of mutual support, organising and acting together, can be a creative one, where new ideas, forms of action, rituals and institutions are generated, adding up to a movement culture.

Motivation and belonging: the energy and sense of belonging that drove the early gay response to AIDS in the US, or the social mobilisations around HIV treatment in South Africa, show vitality and momentum that is often lacking in the externally designed initiatives of health and development agencies.

‘When I got infected it’s difficult to live with it, because the people who were supposed to help you in difficult times don’t want you, there’s no one who wants to help you..... You only think that this is it, I am already dead, there’s nothing I can do.... The first group that I attended.... I met people who are like me, who are also positive.. I never saw something like this before and it encouraged me to know that I am not the only one – we are many.’ | member of ICW, Namibia

Struggles over values and the meaning of development

Social movements create new meanings that ‘frame’ taken-for-granted relationships and institutions differently, and in this way mobilise people to challenge them. They raise questions about what counts as development, and the relationships that underpin patterns of differential access to resources. Crucially, social movements allow people most affected by an issue to have their own say and decide what social change is seen as important.

Framing and values: the women’s movement in Northern Europe and Northern America in the 1960s and 1970s provides a good example of the importance of ‘framing’ social relations in particular ways. Unequal gender relationships were redefined as oppressive and harmful rather than being accepted as ‘just the ways things are’. The way everyday language reinforced inequality between men and women, and assumptions about division of labour, not least the unpaid

domestic work of women, were made visible, framed differently and challenged by the women's movement. The People's Health Movement is another example: this global movement rooted in developing countries, has asserted that health is much more than a medical issue, drawing attention to social and economic impacts of dominant models of economic growth that adversely affect health.⁸

An important insight from work on social movements and poverty is that poverty is best understood and 'framed' as a social and political relationship rather than a lack of assets. In this way, rather than seeing people as 'marginalised' or excluded, it is more useful to focus on the 'relationships of adverse incorporation' that involve them in economic and social life on very unequal terms and naturalise their inequality.⁹

Creative communication

Social movements often develop novel forms of communication and expression - ways to collectively decide on what is important, communicate these priorities and act on them. Such communication may build on existing historical and cultural experiences of protest – what have been called their 'repertoires of contention',¹⁰ but equally, they may innovate new methods rooted in the ongoing struggle and cultural context.

Methods of communication and organising: activists from the Treatment Action Campaign (TAC) in South Africa drew on experiences of involvement in the Anti-Apartheid struggle, to develop a sophisticated blend of court and legal action, international solidarity, media campaigning, civil disobedience and community mobilisation.¹¹ Social movements may develop new forms of expression embedded in local context and culture, such as the 'Toilet festivals' organised by the organisations of people living in informal settlements in Mumbai, India, that drew local municipal officials into negotiations around adequate water and sanitation.¹² They may also make use of new and emerging media, such as the use of the Internet by the Zapatista movement in Chiapas, Mexico, to communicate about their resistance to economic domination by the US in imposed free trade agreements.

Doing 'politics' differently

'We challenge the government a lot, but many times we don't get what we really want from the government. It's like the government are putting us [up against] a brick wall'. | member of TAC, South Africa

Social movements often challenge dominant notions of politics and accountability. Conventional political analysis tended to dismiss social movements as being politically immature and underdeveloped – not addressing the 'real' sources of power and social change by 'seizing the reigns of government'. More recently, social movements in Latin America in particular have been shown to enact a distinctively 'cultural politics' – expanding the boundaries of what is considered political, moving beyond the confines of electoral politics of so-called democracy, to different kinds of participation and involvement in social struggles, novel forms of political expression, and different spaces of public debate.¹³

Social and political opportunities: in attempting to understand how social movements develop, it has been important to look at the social and political environment in which they develop and the opportunities and constraints surrounding them and affecting their growth. Existing networks and resources for mobilisation may influence the growth of movements, although new networks and connections can be as much a result as a basis for social movements.

Changing the 'terms of engagement': by creatively adapting to the social and cultural context, many social movements attempt to change the normal way of doing and seeing things. The 'Toilet festivals' in Mumbai mentioned above, confronted local officials with the realities of living in informal settlements without toilets. By inviting local officials to inaugurate new toilets, they highlighted the constructive initiative of those living in informal settlements, who had organised their own infrastructure. Local officials were also drawn into an engagement over resources and infrastructure, challenging their previous indifference and tendency to focus on issues of illegal settlement. Arjun Appadurai suggests this changed the 'terms of engagement' between the informal settlement dwellers and authorities, even if it had no simple political impact. It was also an important part of developing the aspirations and sustaining the motivation of those living in informal settlements to organise and challenge their situation.¹⁴

HIV social movements

The Treatment Action Campaign in South Africa and the response to HIV and AIDS in the US in the 1980s and 1990s illustrate the importance of social movements in tackling the epidemic.

The Treatment Action Campaign in South Africa is most known for its campaigns focused on ensuring access to HIV treatment through legal battles with international pharmaceutical companies to reduce the price of drugs¹⁵, and maintaining pressure on the South African government to implement an effective national treatment policy. However TAC has also provided a sense of belonging and self-worth for many people living with HIV and AIDS where they had previously been shunned by families and communities. This has empowered many to find new meaning in their HIV diagnosis – even amounting to a 'new birth' as social activists for some.¹⁶ More recently the networks and organisations that make up TAC have turned their attention to the need for broader social support to tackle the multiple challenges of poverty and inequity.

Some have argued that TAC operated more like a civil society network or association than a social movement, given its focused aims and its interaction with the South African government.¹⁷ The range of aspects outlined above however, show that TAC seems to be broader than this, and has much in common with other health social movements. Such studies of health social movements have shown that they usually focus on: access to the provision of health care services and drugs; the experience of illness and disease; and health inequities between different groups.¹⁸ At the same time, HIV social movements have also put emphasis on questions of human rights and the moral and sexual politics of HIV and AIDS, that make it more than a health issue alone.

High profile battles were played out in the media between the South African government and TAC over the existence and role of the HIV virus, and the value and need for antiretroviral treatment. These were essentially communication battles over 'framing' TAC demands as legitimate or not. TAC framed their arguments as a moral issue of sympathy for those with HIV, as well as a question of their rights to treatment. They were careful to appear constructive, and not rigidly opposed to the South African government. The South African government drew on nationalist rhetoric, presenting TAC's campaigns as the un-African actions of a white liberal elite under the influence of pharmaceutical companies. The government also presented itself as defending the African family against racist assumptions of deviant African sexuality.¹⁹

The fact that TAC mobilised predominantly black working class and poor women, and has strong alliances with key constituencies involved in the anti-apartheid struggle, ultimately prevented government attempts to style their campaigns in this way, despite their elite connections. But equally important was the media-savvy approach of TAC, and their use of innovative communication approaches, including treatment literacy campaigns, use of the Internet, use of text-messaging to organise marches and events, and the 'HIV Positive' t-shirts worn with pride by many regardless of their HIV status.

Such battles over meaning that attempt to challenge dominant assumptions are at the heart of social movement struggles. They are also important within movements themselves, where there may be differences of power between those in the movement and some interests over others may become movement priorities. Studies of the early response to AIDS in the US for example, have shown that the concerns of women and ethnic minority communities tended to be eclipsed by the albeit, very effective and creative organising of middle class, white gay men. This influenced the priorities of AIDS organisations in certain ways and inflected the styles of communication and campaigning.²⁰ High profile direct action and campaigning became the priority for many, while the ongoing support and care, that arguably underpinned the wider response tended to be made invisible and was disproportionately carried out by women – reproducing a familiar gendered division of labour.

Working with social movements

Given the tendency for social movements to mobilise in opposition to governments and the status quo, what are the implications for development agencies engaging with social movements?

A review of the experience of TAC and other social movements in South Africa suggests that by representing the interests and voices of the poor and marginalised, and contributing to the restoration of political plurality they are effectively enhancing democracy.²¹ Similar conclusions come from work on social movements addressing aspects of poverty, where it has been noted that they contribute by politicising aspects of poverty and widening public debate.

Some have argued that support to social movements from development agencies risks elevating the views of some above others, upsetting the balance and possibly splitting or weakening a movement in which there may be ongoing power struggles over their focus and priorities.²² In this context, development policy and practice could usefully concentrate on strengthening the enabling environment for movements rather than direct support: through protecting the right to form independent associations, protecting human rights and the right to protest, and supporting social movements to communicate in public debates and be visible in the media.²³ Recent work in Brazil by Panos London and Gestos, has shown the value of supporting different social movements to come together to share lessons on communication and engagement with the media.²⁴

Formal development organisations and processes however, may endanger the very community ownership and involvement so characteristic of social movements. The early response to AIDS in the US for example, saw engagement and ownership by a range of communities and the creation of grass-roots organisations and campaigns. Over time however, as the response to AIDS developed, it was accompanied by progressive institutionalisation and professionalisation, moving further and further away from the communities that originally organised the response with their own resources and initiative. As new formal organisations proliferated, they became more pre-occupied with sustaining funding and impressing influential constituencies than dealing with the real needs of people most affected by HIV and AIDS. Given the demonstrated importance of community engagement for effective prevention, this is a salutary warning for HIV and AIDS responses that become overly bureaucratised.²⁵

It is important to understand better how particular social movements may provide scope for genuine democratic involvement of people most affected by HIV and AIDS. Equally, it is important to understand more generally how much charismatic leadership may mobilise people for less transparent political agendas. The spectre of identity or emotionally based appeals being used to promote prejudice and fear – such as in some ‘ethnic’ and ‘communal’ conflicts in south Asia – shows that the dynamics of social mobilisation and social movements are in urgent need of greater critical analysis.²⁶

References

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- 19 See note 11
- 20 Stoller, N (1998) *Lessons from the damned: Queers, whores and junkies respond to AIDS*, New York: Routledge
- 21 See note 17, p412
- 22 See note 9. This is of course a broader political question accompanying any support and resourcing for different groups or organisations in the context of development.
- 23 See note 9
- 24 See Gestos: www.gestospe.org.br
- 25 See note 20
- 26 Tambiah, Stanley (1997) *Levelling crowds: Ethnonationalist conflicts and collective violence in South Asia*, New Delhi, Vistaar Publications