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Scaling up health promotion interventions in the era of HIV/AIDS: challenges for a rights based approach

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SUMMARY

A sustained scaled up response to global public health challenges such as HIV/AIDS will require a functioning and efficient health system, based on the foundation of strong primary healthcare. Whilst this is necessary, it is not sufficient. Health promotion strategies need to be put into place to better engage and support families and communities in preventing disease, optimize caring, creating the demand for services and holding service providers to account. There will have to be a move away from the traditional model whereby the problem of HIV/TB/malaria is to be solved by merely increasing resources to a centralized bureaucracy that tries to increase the supply of services including health promotion messages. Development projects and programs that succeed are based on understanding of local practice and preferences, rather than on internationally 'generalized models' of how people or villages should behave and what they should want. This paper will first briefly review different approaches to scaling up health promotion interventions, some of the key obstacles in scaling up and then suggest some possible solutions with a focus on a human rights based approach. This approach changes the emphasis from the content of the message to the characteristics of a community's organisations and institutions. Scaling up occurs as a process of association between state actors and civil society that is planned strategically and involves a sharing of experience and a strong learning process among the association partners. A human rights-based approach can facilitate such an approach through developing a common vision, delineating roles and responsibility and facilitating communication channels for the most vulnerable. But this will require health development agencies to pursue a more overt political agenda.

Key words: health promotion; HIV/AIDS; rights based approach

INTRODUCTION

The inexorable rise of HIV/AIDS and the resurgence of many other infectious and non-infectious diseases across the globe has finally led to a recognition of the urgent need for a large scale public health response. Initiatives such as Global Fund and WHO's 3×5 Initiative are manifestations of the new found urgency. A sustained scaled up response will require a functioning and efficient health system, based on the foundation of strong primary healthcare (World Health Organisation, 2003). Whilst this is necessary it is not sufficient. Despite the large investments in directly observed treatment short course (DOTS) for TB, completion rates still range from low (37%) to moderate (78%) (World Health Organisation, 2002). Even simpler regimes such as that for malaria (which rarely exceeds three doses) suboptimal dosing is still seen in 60–70% of cases in Africa (Ansah *et al*., 2001).

Lessons from essential health programmes suggest that even with functioning health systems the results can be disappointing mainly because of the lack of engagement with communities (Zwarenstein *et al*., 1998; Bryce *et al*., 2003). This is especially the case for HIV/AIDS programmes. Research has consistently shown that an effective response to this epidemic will have to move beyond the supply of condoms, health messages for safe sex, etc., and start to tackle issues such as stigma, power networks and kinship systems

(Campbell and Mzaidume, 2002). Communication strategies need to be put into place to better engage and support families and communities in preventing disease, optimize caring, creating the demand for services and holding service providers to account (World Bank, 2003).

The United Nations, and many other international and bilateral development agencies, have endorsed a human rights approach in their development activities. A rights approach is based upon the Universal Declaration of Human Rights, 1948, and the International Covenant on Economic, Social and Cultural Rights, 1966. In addition, references to the right to education and health care are found in the European Social Charter, 1961, the African Charter on Human and Peoples' Rights, 1981, and the Convention of the Rights of the Child, 1989 (Gauri, 2004). Kinney has identified 110 national constitutions that make reference to a right to health care (Kinney, 2001). Health promotion interventions thus need to integrate a human rights-based approach into strategic and effective action plans within the existing resource constraints.

The priority in the next period, therefore, is one of taking programmes to scale but in a manner that empowers individuals and communities to claim their rights, creating a virtuous cycle of improving health systems and healthy communities. This raises a number of critical questions: how to scale up the broader health promotion component of programmes in a manner that addresses the underlying determinants of health? What is the utility of a human rights approach in large-scale health promotion programmes for HIV/AIDS? What are the potential barriers to such approaches? How can they be overcome? This paper will first briefly review different approaches to scaling up health promotion interventions, some of the key obstacles in scaling up and then suggest some possible solutions with a focus on a human rights based approach.

MODELS OF SCALING UP

Carl Taylor (Taylor, 2001) has suggested that there are four models that characterize previous attempts to scale up community projects.

The blueprint approach

In this approach experts select successful interventions from local or international experience. A blueprint is designed by outsiders with the classic features of log frameworks, targets and regulations. Tight supervision and incentives achieve quick results.

The explosion approach

Focused interventions are selected as national or global priorities. Tight control and efficiency are assured by the establishment of a focused and well-resourced vertical hierarchy, which usually duplicates existing management systems. This approach can be effective in filling infrastructure gaps if it is integrated through the whole system. The resulting social mobilization can strengthen the local system but is ultimately destructive and not sustainable if it continues to ignore local priorities. The mass campaigns associated with the ORT, and polio eradication campaigns were modelled along these lines.

The additive approach

This approach focuses on bottom up and culturally adapted development at the community's pace. It is stimulated and financed by outside NGOs with hopes of being phased over to local control. This is the model used by many local and international NGOs. However, phasing over to local control is often difficult because of dependency and because participants are accustomed to outside payment and equipment. This approach is also too slow to rapidly go to scale or fit into a national system; it may require a top down enabling environment for scaling up.

The biological approach

This approach starts with identifying existing successful community-based projects, which demonstrate self-reliant empowerment. Each community is encouraged to become a growth node for rapid expansion. External agents and agencies have a role to play in establishing an enabling environment and supporting community empowerment but also facilitating the sharing of experiences.

APPROACHES TO SCALING UP HEALTH PROMOTION

The first two approaches have been the most commonly used models and are best suited towards health promotion and communication strategies that emphasize particular behaviour

changes. They are based on the belief that people make rational decisions based on the information that is available to them. If they believe that malaria is caused by witchcraft, for example, it is rational for them to hunt witches. However, if they are presented with credible information that malaria is caused by mosquito bites, it becomes rational for them to find ways of stopping bites, and effective anti-malaria campaigns become possible. Typically, health education messages are transmitted to target audiences in time-bound campaigns—through mass media, through communication products such as posters and billboards and occasionally through structured interpersonal communication such as focus group discussion.

This method has been especially successful when used in tandem with campaigns such as vitamin A supplementation, immunization, etc. However, it often proves difficult to sustain these gains when the behaviour change campaigns stop. For example, in Sub-Saharan Africa despite impressive increases in coverage at the beginning of the 1990s (mostly as a result of large scale campaigns) 20 out of 53 countries showed a decline in measles coverage by 1999: all of them having a coverage below 75% (Labonte *et al*., 2004).

There is increasing evidence that even when high levels of knowledge have been achieved through behaviour change messages, individual practice may not change accordingly. In a study of home-based management of malaria in Ghana, for example, 71% of mothers could accurately recall how to administer anti-malarial drugs, but only 15% gave the correct drug at the correct dosage and times; 63% of mothers knew that a child with fever should receive tepid sponging and antipyretics, but only 3% actually practiced this treatment. (UNICEF, 2002). The unidentified factors that prevent individuals from acting on rational information may be the social and cultural practices embedded in communities. In Kenya, for example, the *Luo* practice widow inheritance (*joter)*. In its traditional form, the inheritance of a relative's wife ensured that the widow and her children were not destitute. Today, the practice of *joter* can spread HIV: if a man infects his wife with the virus before he dies, she will likely infect the relative who inherits her (Gonza, 2000). Stigma has been identified as an important barrier to effective community engagement on HIV/AIDS issues (Nyblade *et al*., 2003). Health communication campaigns to counteract stigma have made little impact to date as they underplay not only the deeper cultural and social norms and almost completely ignore the deeper structural determinants that perpetuate such phenomena (Parker and Aggleton, 2003). Many women, for example, do not have the social standing or negotiating power to convince their sexual partner to wear a condom (Ford *et al*., 2003)

Despite its manifest shortcomings this approach continues to dominate. We believe this can be partly explained by the way in which this fits with the predominant development paradigm. Taking their cue from what Scott (Scott, 1998) has called the 'high modernism of the state', central and local bureaucracy across the globe have aspired to reinterpret development problems into 'engineering' problems amenable to modern management techniques. So the challenge becomes one of measuring 'needs' and thence specifying resources and supplies to be provided. This can then be easily mapped into corresponding budgets, targets, goals and plans. Studies from numerous sectors have shown the failures of this approach basically because, as Pritchett and Woolcock put it, 'the lack of feedback mechanisms and modes of engagement of citizens in either controlling the state or directly controlling the providers allowed systematic problems of organizational design to overwhelm logistics' (Pritchett and Woolcock, 2004, *ibid*:199)

In their review of successful rural development projects Uphoff and colleagues (Uphoff *et al*., 1998) warn of taking a 'cookie cutter' approach where scaling up is viewed merely as replication (i.e. the blueprint approach) since this underplays the need to build the capacity and confidence of project participants. Community participation has usually meant getting community organizations to carry the education messages to their constituencies.

If we are to change entrenched cultural and societal norms, that have such an important impact on the effectiveness of health programmes, then a more 'biological' approach is required. This approach changes the emphasis from the content of the message to an analysis of the characteristics of a community's organizations and institutions. By trying to nurture strong and inclusive community-based organizations it increases social cohesion and thereby reduce a population's vulnerability to HIV (Barnett *et al*., 2000). Scaling up occurs as a process of association that is planned strategically and

involves a sharing of experience and a strong learning process among the association partners.

This can be exemplified by the well-documented success of Uganda in reducing HIV prevalence mostly through a shift in the behavioural profile of the population especially reductions in the number of sexual partners (Shelton, 2004). Low-Beer and Stoneburner have put forward a cogent hypothesis, based upon extensive survey data, that the personalization of risk occurred much earlier in Uganda than other countries in the region (Low-Beer and Stoneburner, 2003). Sufficient personalization to shift the distribution curve of risk behaviour occurs when ~90% of the population know a person who has died from or is living with AIDS. Uganda reached this level when HIV prevalence was at ~5–10%, while in other countries it required an HIV prevalence of ~20% to reach the same level of risk personalization. The authors argue that this has been largely due to a general openness to the discussion of AIDS and a national policy that discourages stigmatization. This in turn was built on the fertile ground of a society with high levels of social contact and co-operation, commitment to and satisfaction with organization and community and productivity and innovation at organizational and community levels.

HUMAN RIGHTS APPROACH TO HEALTH PROMOTION

According to the 2000 Human Development Report (United Nations Development Programme, 2000) human rights represent the claims that individuals have on both the conduct of individuals and the organization of social institutions to facilitate or secure the capabilities and freedoms necessary for human development.

Development *with* community members is a core component of UNICEF's human rights-based approach to programming (HRBAP) (Jonsson, 2003). In this conceptual framework, health promotion is acknowledged as an ongoing activity within a community—unlike campaign-style communication, which is seen as a distinct activity carried out by professionals. People communicate constantly as they make daily decisions, explore strategies for surviving and coping, discuss norms and standards to apply in their communities, absorb and apply new information and experience and affirm themselves. This ongoing communication reflects existing power relationships and can therefore either support or constrain people's choices. People adapt and change their survival and coping strategies as the communication around them makes new information available, or places it in a different context. They make decisions by assessing their situation, analysing its causes, and acting, which leads to a situation that must then be re-assessed and re-analysed, continuing the cycle. This 'Triple-A' construct represents a process of 'learning by doing' (Castelloe and Watson, 1999).

The task of engaging community members in a development agenda that they themselves set becomes an exercise in facilitation rather than one of designing and delivering messages. External agents—either from the state or NGOs—can help community members 'define who they are, what they want and how they can get it' (Rockefeller Foundation, 1999) by creating spaces and channels for people to discuss issues amongst themselves—and by connecting community groups that do not usually communicate, such as elders and youths. They can then improve or create communication channels between communities and government departments and/or development agencies, so that people can negotiate for their own development priorities more effectively. Facilitating this dialogue, and creating safe spaces for people with different perspectives and different social standing to exchange viewpoints, becomes the principle task of health promotion.

A human rights approach to programming builds on this approach by seeking to improve the relationship between claims holders (community members) and duty bearers (people in authority, either from government or development agencies) so that ordinary people can realize their right to survival, health and development, and those in authority can fulfil their responsibility to govern effectively. In Eastern and Southern Africa, UNICEF has developed a structured approach to this process that includes the following steps (Jonsson, 2003).

Step 1: causality analysis

Advocacy and social mobilization are key strategies in increasing awareness of an issue. The causes of the issue can then be determined at immediate, underlying and basic levels—with the assistance of an appropriate conceptual

framework, and through the use of participatory research methodologies.

Step 2: role or pattern analysis

Key actors, including children, parents, school teachers, community leaders, district authorities, etc., are all both claim-holders and duty-bearers. The interaction between these groups forms a 'pattern' of claim–duty relationships. Often a particular duty-bearer cannot meet his/her obligations because some of his or her rights are being violated. Parents without resources cannot be held accountable for not being able to pay school-fees that are too high. Determining the pattern of rights and duties around a development issue is a crucial step in the human rights-based approach to programming.

Step 3: capacity analysis

Once the principle duty-bearers responsible for resolving a development issue have been identified, the next step is to analyse why they cannot perform their duties as expected. This is called a capacity analysis. It entails a systematic assessment of responsibility, motivation, leadership, authority, resources, capability to communicate and capability for rational decision-making and learning in key duty-bearers and claim holders.

Step 4: identification of candidate actions

Consensus on what to do is reached through dialogue between community members and facilitators and other potential actors outside the community. At each level of society, some actions should aim at developing capacities of claim-holders to claim their rights, while others should aim at developing capacities of duty-bearers to meet their duties. This analysis result in a structured list of candidate activities required to achieve development goals. Planning and implementation of these activities can then proceed in a manner consistent with participatory development.

BARRIERS TO SCALING UP SUCH APPROACHES

The recognition of the importance of community based development has been recognized and promoted for a number of years and yet there are still only a few examples of successful large scale community based programmes. Barriers to scaling up such approaches include (Binswanger and Aiyar, 2001).

Differences in the values and experiences of the co-producers

Community members or local NGO members have different perspectives than the external consultants or state agents who quite often underestimate the community capacity and experience.

Poor delineation of roles and responsibility

Community development is a complex process and successful co-production on a large scale requires specific actors at different levels to be clear of their roles, how to do it, and what tools to use (forms, questionnaires, technical approaches, training materials, etc.). There also needs to be mutual recognition of the roles and responsibilities between state and community actors.

Lack of institutional capacity

As mentioned above complementarity depends upon the ability of the state to set the environment for decentralized actions. Such capacity at both the central and peripheral setting is usually sub-optimal.

Lack of communication channels for the most poor and vulnerable

Public sector workers are more likely to relate to dominating interests within communities. There is a danger that interventions may re-enforce existing inequalities within communities.

OVERCOMING BARRIERS TO ENGAGING COMMUNITIES AT SCALE—THROUGH THE USE OF A HUMAN RIGHTS PRINCIPLES AND PROCESSES

We believe that a human rights-based approach can play a critical role in overcoming these barriers. Essentially the HRBAP has an ethical basis (Jonsson, 2003). It requires an ethical analysis of *why* development activity should occur (motivation), *what* should be done (outcomes)

and *how* these outcomes should be achieved (process). The principals of solidarity with poor people self-determination, inclusion, participation and social justice feature strongly in HR approach and can be used as a basis for developing a joint values and vision. Differences in the values and experiences of the co-producers, can be mitigated by the principle of appreciation—learning to value the opinions and background of other actors in the development process.

UNICEF Malawi has used human rights principles and processes to engage communities around HIV, using a process called *community dialogue* to start discussion about children who have been orphaned or made vulnerable by AIDS. The dialogue has been facilitated by local government workers who are often community members themselves. Facilitation includes techniques from *Participatory Learning and Action* (Pretty *et al.*, 1995), including community mapping to show where vulnerable children live and transect walks to orient community outsiders to the local situation. It produces a Village Action Plan that clearly identifies the roles and responsibilities of community members and local government workers, enabling co-production to take place.

A Village Action Plan, for example, may call on the village chief to provide land for a community garden that would benefit orphaned children. It would require community members to provide labour for the garden, and local government authorities to provide fertilizer and seeds. Each Village Action Plan is different; each responds to the local situation in the way community members think best, with information and technical support provided by local government workers. The result is an 'at scale' (district-wide) response that is composed of many different community responses. This 'at scale' response is resource-efficient for governments and development agencies: in the example above, co-production enabled them to create a garden with minimum expenditure.

In many resource-poor communities and countries, traditional communication channels between claim holders and duty bearers have broken down, either because of social disruption or institutional hostility. Many claim holders—especially women, young people, the poor and the sick—are unable to communicate effectively or to participate in decision making equally because of their low social or economic status, and/or their limited access to information and communication technology. A human rights perspective seeks to give a voice to these voiceless claim holders, so they can express themselves and be heard in modes that are indigenous and authentic to them (Ford *et al.*, 2003). Increasing connectivity between claim holders and duty bearers and building capacity in both groups to effectively listen to each other, understand, plan and act collaboratively are two important strategies. This means that international organizations, such as the UN, have an important advocacy role to play in ensuring that national and local institutions allow an HRBAP to occur. Through senior-level discussions, they can advocate that governments in developing countries:

- provide adequate resources for community-based health programmes in national budgets;
- decentralize government financial authority to local levels so that resources are more readily available to communities;
- identify all possible groups of facilitators—faith-based organizations, NGOs, CBOs, farmers' co-operatives, teachers' associations, etc., and mobilize them in support of community-based health programmes based on HRBAP;
- identify common aspects of community action plans and support them with appropriate mass media campaigns.

A valid critique of such an approach is that it continues to ignore a reality in which does not involve 'equals' in a transparent network exchanging nuggets of information, but socially embedded individuals, whose lives, bodies and practices are all structured by power relations and negotiated meaning. As Cromwell (Cromwell, 2003) points out in her recent review of participatory methodologies:

> With their emphasis on consensus, the institutions created as part of participatory development initiatives—whether committees, user groups, community action planning groups and so on—can exacerbate existing forms of exclusion, silencing dissidence and masking dissent (ibid:1328).

Social theorists such as Castells and Bourdeu remind us that in addition to the overt mechanisms of control such as propaganda, economic power, etc., national elites are increasingly relying upon control of new technology and information, reproduction of nationalistic and institutional 'myths'. All this suggests that if the

space for a set of democratic structures that facilitate co-production is to be created, international organizations such as the UN need move from a simplistic notions of supporting social mobilization (cf. Polio campaigns) towards a more overtly political engagement with social movements, civil society and governments. In other words the process of identifying the duties, roles and responsibilities for upholding the rights of the most vulnerable must be conducted at all levels—local, national and global—not just as a community exercise.

CONCLUSION

It should be clear from the above analysis that governments and development institutions must adopt new roles and responsibility to achieve sustainable gains in survival, growth and development. By this we mean that there will have to be a move away from the traditional model whereby the problem of HIV/TB/malaria is to be solved by merely increasing resources to a centralized bureaucracy that tries to increase the supply of services including health promotion messages. Development projects and programmes that succeed are based on understanding of local practice and preferences, rather than on internationally 'generalized models' of how people or villages should behave and what they should want. Quality scaling up should involve multiplication through adaptation not replication. There is a need to move to from blueprints to frameworks. The biological approach recognizes the critical role that external agencies have in facilitating the scaling up of community projects. Obviously central to this is the need to strengthen organizational and learning capacities of not just communities but also local bureaucracies. This highlights the importance of the relationship and roles of local community actors and outside state or agency actors, especially in fostering the democratic structures that lead to co-production. This democratic space in turn has to be fought for at the national and international level.

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