Building partnerships to respond to HIV/AIDS: non-governmental organizations and universities

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Background: In the second decade of the AIDS epidemic in Brazil, public sector and non-governmental organization (NGO) initiatives multiplied, fostered by state AIDS Control Programmes. A growing gap between capacity and a need for programme evaluation and the dissemination of findings from experience in the field, combined with the failure of traditional training approaches to bridge this gap adequately, inspired this non-degree research training programme at a major Brazilian university.

Objectives: To train health professionals and activists working with HIV/AIDS prevention and services to evaluate and disseminate their experiences, and to enable them to multiply this training in their organizations, working in a collaborative process with graduate students and senior researchers.

Procedures: As part of a 9-month research methods course, 52 representatives from NGO and public health services produced research protocols that were reviewed and strengthened through a formal peer review process. Eleven protocols judged to be the best received funding and close mentorship over the next 21 months for their implementation, analysis, and dissemination.

Lessons learned: Participants increased their ability to master and review critically the AIDS literature, to conduct a research protocol and to disseminate the results of their studies. After completion of the 30-month process, many participants were able to present their findings at scientific conferences or publish their results in peer-reviewed scientific journals. This model of close NGO–university successful collaboration may inspire other models of research training for those in the front-lines of the fight against the epidemic.

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Introduction

Brazil is a country of profound social inequalities, resulting from a development process that has exposed millions of its citizens to extreme poverty, social exclusion and violence, making large segments of the population vulnerable to HIV. United Nations indices of human development have consistently placed Brazil in approximately 70th place. Despite the social vulnerability of the Brazilian population, Brazil's AIDS Programme has had relative success in controlling the growth of the epidemic. Thanks to universal access to antiretroviral medications, including protease inhibitors, through the public healthcare system, the Brazilian Programme has also achieved other crucial gains, including a 50% reduction in the AIDS mortality rate [1] and an improvement in the quality of life for those living with AIDS [2].

What elements of the 'Brazilian model' can explain this success in such a highly vulnerable social context? The situation is complex, and this question does not have a

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simple answer. A general consensus in the debate about the Brazilian experience, however, is that one of the key reasons for the success of the programme has been the consistent collaboration between organized civil society, represented by non-governmental organizations (NGO) and government agencies [3]. A dynamic interaction of non-governmental initiatives and government-led programmes has succeeded in rising to the challenge of bringing HIV prevention to the most vulnerable population groups and making care available to people living with HIV.

We have seen that the pressure and organization of those most affected by the epidemic, expressed through NGO and human rights activists, was fundamental in Brazil as it has been elsewhere in the world [4]. Even before the AIDS epidemic the social movement known as 'Social Medicine' [5], a productive coalition of academics, public health professionals and NGO, resulted in a public health approach that emphasizes a sociological and political understanding of collective health phenomena. Brazil had a tradition of progressive health policy and social medicine, which since the 1970s has dominated academic public health in Brazil. This background stands in stark contrast to a mercantile approach, which views individuals and target groups only as potential consumers of ideas, services, and products. This heritage enabled Brazilian AIDS policy makers to be more open to prevention centred around 'popular education', building on the principles of Paulo Freire [6], and sensitive to the relationship between health and social processes. Similarly, proposals for interventions took into account not only technical efficiency but also the need to respect and promote the social and political rights of individuals with HIV and vulnerable populations.

The need to build evaluation skills

In 1995, the first set of programme evaluations was initiated in Brazil, as part of 'AIDS I', a programme financed by US$250 million in World Bank funds plus more than US$90 million in national counterpart. Evaluations from the implementation process validated the importance of local partnerships, funding NGO and diverse public services [7]. Meanwhile, the construction of new models for prevention continues to take place amid the understanding that various AIDS epidemics presently co-exist in Brazil [8].

The number of people involved with prevention programmes increased, and several NGO sprang up in many regions of the country and proliferated with support from the Ministry of Health and many international agencies, especially those that had experience in the fields of population, development, and health. Nevertheless, programme evaluations were seldom rigorous or systematic. Training and technical support for the evaluation and dissemination of results for those involved in prevention programmes was almost non-existent.

Since the very beginning, those responsible for governmental and non-governmental initiatives in the field of prevention faced the challenge of providing information about their intervention projects, even though they were not usually familiar with the 'rules of the game' for the international scientific literature. Written materials prepared and distributed by international agencies that attempted to address this deficiency did little to help the situation. The ideas that circulated in these materials were strongly influenced by North American and European responses to AIDS. This dominance did not stimulate professionals in Brazil to value our local expertise in education, health promotion, and most notably the Latin American tradition of popular education, the relevance of which is now internationally recognized wherever inequality and poverty open the door to HIV infection [9,10].

At the same time, there has been a widening gap between the skills provided by traditional education and the rapid growth of new NGO and services needed to confront the epidemic. Cavalheiro [11] described how representatives from even the biggest and most prestigious NGO in São Paulo, even university-educated activists and professionals, had difficulty reading the scientific literature, little practice in consulting recent references in this rapidly evolving field, and consequently great difficulty in writing well about their own work.

In response to this problem, the Ministry of Health, after a reorganization of the National AIDS Control Programme in the mid-1990s, sponsored a few workshops on research design and evaluation. These were mostly taught by professors from outside the country. This strategy had several important limitations, including the distance between the training site and the everyday practice of professionals in the front-lines, a lack of continuity of teaching and support, and insufficient time for incorporation of feedback and the development of mature research proposals during the timeframe of the workshops (2 or 3 weeks).

At the same time, existing 'international training programmes for developing countries' had their own limitations. In one of the best such programmes, sponsored by the Fogarty International Center of the National Institutes of Health, most of the resources are used to bring trainees to the United States for formal postgraduate degree programmes. This presents a number of problems: participation is limited to those who speak fluent English; costs per participant are extremely

high and out of proportion to local needs and realities; and such programmes remove participants from their communities for long periods of time, with many never returning.

It was therefore necessary to create new models that could realistically develop a local model for providing the training so badly needed by those fighting the AIDS epidemic, the programme that we describe here is one example.

The NEPAIDS AIDS Research Training Programme

Based on the need described above, the AIDS Education and Research Nucleus of the University of São Paulo (NEPAIDS) undertook an initiative to provide a non-degree training in research methods and evaluation. The programme was targeted for professionals and activists working with NGO and local health units. The goal was to encourage and facilitate systematic evaluation and the publication of studies resulting from front-line experience with HIV and AIDS prevention programmes, as well as to facilitate a long-term collaboration between the university and some of the most creative organizations working against the HIV epidemic.

The objective of this training programme has been to help professionals in these organizations to become multipliers and disseminators of scholarly reflection about their practices. The idea was to take advantage of the insights gained from their experience, stimulating the formation of research questions and innovative approaches to the challenges of prevention, without removing them for the long time necessary to obtain a formal degree or luring them into academic careers.

Demonstrating the strong demand for this type of programme, more than 115 individuals applied to participate. Applicants ranged from graduate students to high-level professionals from various cities throughout and around the state of São Paulo. A total of 52 were selected to participate. The selection criteria emphasized the relevance of the candidate's institution to the response to the epidemic in São Paulo or his/her district of origin. This relevance was not measured so much by the size or public recognition of the institution, but primarily by the history and likelihood of the candidate and organization working with more vulnerable groups, people less well served by existing government programmes or less likely to be reached by the usual approaches to prevention.

Among the 52 participants, 35% were university-educated activists representing NGO. The same number were representatives of government health programmes, with a similar profile to the NGO activists, because they came from the front-lines of the fight against AIDS. The remainder were graduate students from the University of São Paulo and other universities. The participants that represented NGO received a small stipend (US$150) during the course as well as financial support for travel, seminar fees, photocopying, and work-related materials.

Without charging tuition, the resources of our public university, including its professors, libraries, regular courses, and internet access were at the disposal of these students and their organizations. The programme also incorporated pre-existing international collaborations with initiatives similar to ours in other countries [12], thereby strengthening global solidarity while acting locally. The core faculty included professors from various disciplines – preventative medicine, social psychology, epidemiology, statistics, anthropology and sociology. To finance the programme, we received sponsorship from the World AIDS Foundation and from the São Paulo State Sexually Transmitted Diseases/AIDS Programme.

The programme was structured to provide familiarity with the latest literature, including scientific and specialized articles, both electronic and on paper, and to give participants training and experience in the elaboration of a rigorous research protocol. Based on the philosophy that the participants' creativity and practical experience should serve as the basis and a guide for their learning, much of the theoretical content was selected individually, according to its relevance to the conception and development of each trainee's own work. This interactive apprenticeship model challenged participants to move forward from their everyday work experience to a higher level. The idea was for the participants, with close supervision from professors, to create lasting channels of learning and debate that would continue after the formal programme was over. Theoretical classes about methodology were therefore only one of the programme's components.

The theoretical framework that oriented the training strategy and defined the programme was based mainly upon the concepts of vulnerability [13–15] and harm reduction [16–18], the constructivist theories of sexuality and sex [19–21], the tradition of education to promote psychosocial change, subject emancipation, full citizenship [6,19], and the promotion and protection of individual and collective human rights [22]. The tradition of 'social medicine' is crucial to this shared background [5].

The topics that emerged within the projects included: evaluation of services and programmes, such as home care or reproductive health services in slums; elaboration and validation of instruments to measure know-

ledge, perceptions, attitudes, and practices regarding AIDS, drug use and prevention among diverse population groups, including adolescents in public schools, young soccer players, incarcerated teenagers, young female sex workers, female carriers of HIV, and patients taking antiretroviral medicines; and research on social vulnerability to AIDS in groups such as adults and teenagers living in slums, inmates in the juvenile detention system, truck drivers, bus drivers, drug users, male and female sex workers, elderly men and women, convicts, and married men living in poor neighbourhoods.

Programme development was divided into three phases. In the first phase, conducted over 9 months, the group met for 12 h per week attending classes and mentorship group meetings, working towards the elaboration of a complete research protocol, including the background, objectives, methods, analysis plan, ethical aspects, timeline for execution, and bibliography. In the second phase, the best projects developed in the first phase were selected to receive financial and technical support for field work lasting one year. The third phase, which took approximately 9 months, provided support to the participants in the analysis of their data and the writing of a report of their results in the form of a manuscript suitable for publication. As a 'rite of passage' for each of the three phases, we met for 3 days to peer review what each participant had produced. From the second phase on, all trainees had the opportunity to participate in all public sessions and lectures organized at NEPAIDS and take other University of São Paulo courses.

On the basis of relevance and ethical and academic quality, 11 projects were selected to receive financial support at the end of the first phase, and were given budgets of approximately US$5000. Each project was conducted in a maximum of one year, with ongoing supervision from mentors and collective discussions with other programme participants. Several projects were conducted in teams, often involving more than one participant in the same project. The graduate students were encouraged to collaborate with and integrate their dissertations into the research protocols initiated by the NGO and health service participants. All participants were included as co-investigators in the collaborative projects that resulted. At no time were the participants removed from working in their organizations of origin, and they were able to share with their colleagues the knowledge, accomplishments, and discoveries resulting from the process.

The last phase was analysing and disseminating the results. This phase included small group teaching activities and a 2-day seminar at which questions and concerns were dealt with interactively. As in the first phase, we used data analysis from projects dealing with areas similar to those being studied by the participants as our didactic examples. The seminar included lectures and practical advice from guest professors and researchers and the review of relevant articles. We studied both positive and negative examples of articles published in specialized journals, proceedings of conferences, and other media of dissemination so that participants could learn from these experiences and avoid repeating errors.

We jointly evaluated the needs of students to strengthen their concepts and theoretical frameworks for analysis, especially for those dealing with qualitative data and process analysis, which were the approaches chosen by the majority of participants for the articles they wrote. We therefore organized a course of eight lectures (32 h) and a reasonable reading load focusing on examples of the application of these concepts in published articles and books.

After this training in analysis, the participants were given a final deadline to submit a rough draft of an article. These served as the basis of a 4-day workshop held outside the city and directed by six professors. The workshop combined formal feedback from assigned peer reviewers (both faculty and co-participants) with periods for group discussion of the manuscripts and free time to work on writing and editing with assistance from all involved.

Lessons learned

The individual and group process evaluations indicated that the training process had amply achieved its goals. The participants were able to increase their ability to read the dynamic literature about AIDS; to systematize, plan, and critique a research protocol; and to analyse and disseminate their results. Without leaving the front-lines of efforts to prevent new infections and care for those already infected, the students learned to value the organized dissemination of their experience and interaction with peers working in academia, in their own or in other service organizations. Several participants who were graduate students took advantage of their contact with activists and professionals in health services to develop dissertations that sought to answer 'hotter' research questions relevant to the dynamics of the epidemic on a day-to-day basis.

Table 1 gives some indicators of the outcome of participation in the programme by trainees who conducted the studies designed during the programme. Without leaving their activities in the public health services or NGO, the majority of participants who successfully completed the programme were able to

Table 1. Productivity of trainees after the AIDS Research Programme.

	National	International
Theses		
Master's degree[a]	7	–
Doctoral degree	1	–
New projects (with external funding)		
Having the trainee as a PI or co-investigator	5	3
Fellowships[b] (NGO/service trainee who became graduate student)	3	2
Publications		
Peer-reviewed journals	9	3
Chapters in books	2	–
Educational booklets	3	–
Other journals	3	3
Academic conferences and seminars		
Panels	8	2
Oral presentations	17	5
Poster presentations	8	13
Published in conference annals	17	17
Participation in:		
Working as a trainer (courses, classes, workshops, etc.)	39	–
Special advisors for public clinics and programmes[c]	11	1
Consultancies for NGO	3	1
Research assistants or co-investigators	15	–

NGO, Non-governmental organizations; PI, principal investigator; UNDCP, United Nations Drug Control Program.
[a]Completed degrees only. Three additional trainees entered graduate programmes and several of those who were graduate students have now entered PhD programmes with a project on HIV/AIDS.
[b]Two from national agencies: CNPq, CAPES/IMS, one for the MacArthur Foundation and one from the Ford Foundation.
[c]Five of our students are government employees in high-level advisory committees or posts; four are now teaching at universities. One is an advisor for UNDCP.

publish reports of their research in specialized journals [23–25] and books [26,27] or to produce educational materials for dissemination about sexual and reproductive health [28–30]. Almost all of the participants who stayed with the programme from start to finish presented their work in research conferences or national conferences and meetings. Several papers and dissertations [31–38], which resulted directly from the research studies conducted under this project have been published in peer-reviewed journals [25,39–49]. Many trainees have been technical advisors for various organizations, and others upgraded their positions in public health services or in community-based health prevention and care.

Many of the organizations that the participants represented improved their status as reference groups in the forefront of the fight against the epidemic, at the same time that the individual participants advanced their careers. For example, the Specialized Ambulatory Care Center of Santana, a public healthcare unit [46], subsequently became recognized as a gold standard programme, receiving public awards and funding for its innovative work and projects. It has organized various courses and training programmes for other centres, initiated six new research studies with various collaborators, and had three of its staff who participated in our programme enter public health master's programmes, one of whom (a social worker) was promoted to director of the centre. Another trainee, who entered the programme representing an AIDS education NGO and completed a resulting collaborative project [38], subsequently initiated a bigger project funded by the Ministry of Health, and then gathered other 'harm reduction' workers and researchers together to found a large new NGO ('É de lei' – conviveredelei@uol.com.br), which has become a reference centre for AIDS prevention and support targeting drug users in São Paulo.

The faculty group who initiated this project has seen its number of dedicated members grow. Based on the success of the experience described here, they have continued to apply and refine this model of research training, including several ex-trainees as co-mentors in a second course in the city of Ribeirão Preto/SP (in one of Brazil's highest AIDS incidence areas), and in a third course being conducted since 2001 in São Paulo in collaboration with the Fogarty International Center, the São Paulo Municipal AIDS Control Programme, and the Ministry of Health.

The need for initiatives of this kind continues and grows. In a country with profound social and economic inequalities such as Brazil, the challenges involved in mounting an effective response to the AIDS epidemic are enormous, and there is little margin for error. To construct such a programme, the full participation of NGO is crucial and we must learn from their experiences and disseminate this knowledge. We believe that initiatives such as the one described above can make an important contribution to this process. Equity, sustainability, and the extension of the accomplishments already achieved will be huge challenges for the future of the Brazilian response. The experience described above gives us renewed energy and demonstrates that the university can be more intelligent and front-line services more effective insofar as they are able to communicate and work with each other.

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