



An AIDS Community Perspective on the Brazilian AIDS Program

*The Implementation of Antiretroviral Therapy
in the Developing World: Brazil and Beyond*

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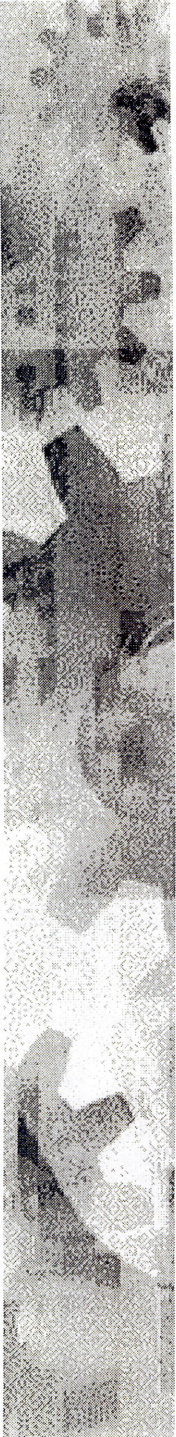
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GRUPO
pele **Vidda** RJ



What is Grupo pela VIDDA-RJ?

- ✱ The first Brazilian PWA organization; founded in May 1989.
- ✱ VIDDA stands for Empowerment, Integration and Dignity of the Diseased of AIDS.
- ✱ The group works in six different fronts:
 - ✱ Self-help activities (women's, men's, transvestites', youngster's, Positive Café, *Tribuna Livre*)
 - ✱ Prevention through lectures in schools, factories, universities etc).
 - ✱ Assistance/care: counselling, free legal advice and support, and the Rio Buddy Project.
- ✱ Information through a hotline, website, brochure, regular publications and the frequent presence in the media.
- ✱ Empowering PWAs and AIDS activists in the annual National Meeting of PWAs, regular seminars and workshops.
- ✱ Political representation at the different AIDS policy making fora:
 - ✱ National Commission on AIDS;
 - ✱ National Committee on Anti-HIV/AIDS Vaccines;
 - ✱ UNAIDS-Theme Group;
 - ✱ State Forum of AIDS NGOs



What is the social movement in Brazil?

- Over 600 community based organizations working in the fight against AIDS, roughly 300 working exclusively with AIDS.
- Organized since the late 1980's in meetings to decide common political goals in the national level, the NGOs started characterizing a unified movement.
- This movement has three major gatherings and/or conferences:
 - National Meeting of AIDS NGOs (discuss the national policies and deliberate on community representations at the policy making for a). Every two years
 - State For a of AIDS NGOs (monthly meeting on most states discussing state policies and national represent).
 - National Meeting of PWAs (yearly GPV/Rio & Niteroi).



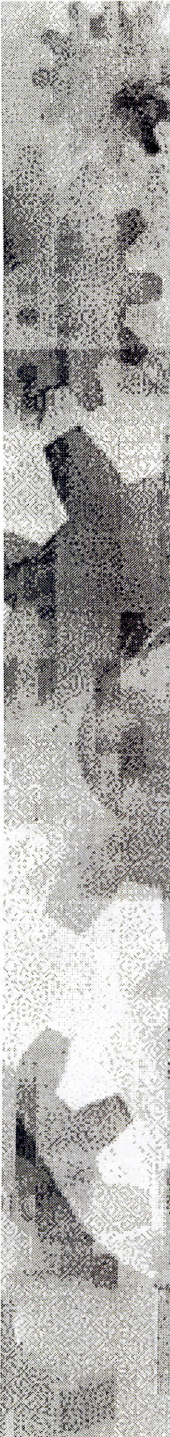
How these organizations work and get funded?

- ✱ Very limited financial and technical resources.
- ✱ Different financial sources:
 - ✱ local partners, sometimes State or Municipal Health Authorities, sometimes other governmental members.
 - ✱ International cooperation agencies, foundations and charitable organizations since early 1980s;
 - ✱ Federal Government (Nat AIDS Program), since 1993.
 - ✱ Donations by individuals and private sector: very small (nothing comparable to private donations in the US or public donations in EU).



Short Brazilian Epidemiological Overview

- ✱ Roughly 203,000 accumulated AIDS cases in Brazil, Dec 00 (prior Epidemiological report Sept. 2000 196,016: 13,9% / N:100,000 (Jan-Sept 2000);
- ✱ Roughly 100,000 “officially” people living with AIDS (compulsory register / reality);
- ✱ Difference in the estimation of infected population: the government estimates 600,000 people HIV+; the community estimates up to the double (1,200,000 people). Reason: of.increase in 30% from last year.
- ✱ Justification: studies carried by community researchers and public health professionals; GPV itself has carried a qualitative study on AIDS care on emergencies of public hospitals and found sometimes a prevalence of 22%, but no actual diagnose or report.
- ✱ Interiorization / Empoverishment / Feminization



How the community sector provoked this response from the government?

- ✱ **1st.** Identifying the key persons in the Ministry of Health and other governmental sectors willing to work for the cause with no underlying interest (no corruption).
- ✱ **2nd.** Creating a good communication with the government, sometimes even planning the actions together (e.g. demonstrations and legal procedures).
- ✱ **3rd.** Creating an understanding atmosphere with the other sectors (governmental and private) as the complementarity of each one's role
- ✱ **4th.** Lobbying for specific legislation (e.g. Lei Sarney that guarantees the provision of treatment by the State; other state or municipal legislation)
- ✱ **5th.** Monitoring constantly the acquisition and distribution of medication, as well the AIDS related care services (helping providing better services).



Examples of how the Social Movement made possible the access to treatment:

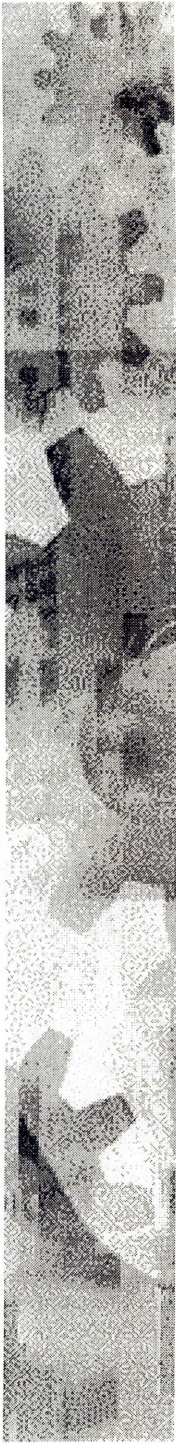
(a) suing the State to provide:

- ✱ The observance of the Labour rights of PWAs;
- ✱ The coverage by the private insurance, as well the coverage by the public Health System of treatment;
- ✱ The free distribution of medication for all Paws.

(b) working with the media to create a favourable environment not only with the public opinion as well as in the Legal System;

(c) working directly with the judges, convincing them to decide favourably to the PWAs.

(d) pushing the local health authorities to start providing medication themselves (first regular provision has been made by the States of Rio de Janeiro and Sao Paulo and Municipalities such as Santos (SP), Rio de Janeiro (RJ) and others.



Successful experiences in monitoring the services:

- ✱ Rio de Janeiro State: often discontinuation of distribution of medication has been solved by:
 - ✱ Direct contribution of community members in monitoring and helping managing the distribution of medication (schema of distribution for the Health Care Centres).
 - ✱ Transferring to the Municipal Health Authority the responsibility of distribution of medication from the Federal Government
- ✱ Ceara State: discontinuation of distribution in smaller cities has been solved by creating direct communication of the local organizations and the State Health Authority (AIDS Program).
- ✱ Sao Paulo State: The problems in distribution at the Capital (Sao Paulo City) has been partially solved with the coordination with the State Health Authority.



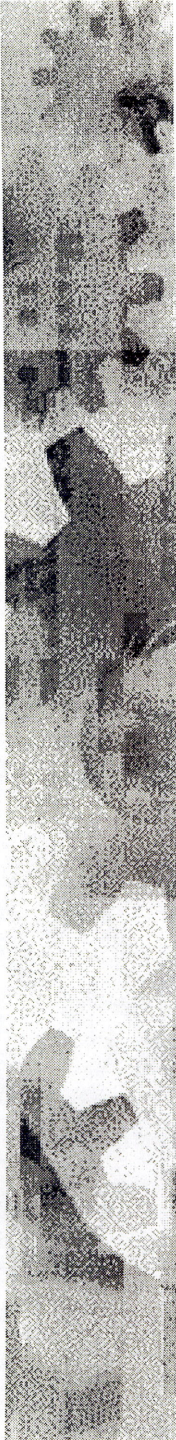
How do you make the program of distribution sustainable?

Creating specific legislation which assures the sources of funding. Global Fund , for smaller economies. For more stable economies, the National Treasure (tax payers' money) has to cover the acquisition of meds.

- ✱ Our role: PERMANENT MONITORING to
 - ✱ a) keep open the budgetary line for the coverage of new treatments,
 - ✱ b) to guarantee the coverage of the actual treatments

States and Municipalities should cover the expenses of treatment for opportunistic infections and prophylaxis;

- ✱ Our role:
 - ✱ To push the local health authorities to implement the budgetary line to cover the acquisition of medications for opportunistic infections and prophylaxis and monitoring the distribution.



Cost effectiveness of distribution of medication:

- ✱ Reduction of cases in 40 to 50% in the death rate that we observe today, has gradually started in 1995 to 1996 when a few states have started the distribution of medication for opportunistic infections and prophylaxis. The actual distribution in large scale of anti-retrovirals started in 1997. Therefore:
 - ✱ The state has reduced in hundreds of millions of dollars the expenses with patients in hospitals in the Unified Health Sys;
 - ✱ People are living longer and therefore able to produce and to contribute to the State;
 - ✱ The local production of medications allow the increase the number of treatments offered, as the cost per patient/year has decreased from 10-15,000 US Dollars to 4,500 USD.
 - ✱ The high impact of the activities of the Brazilian National AIDS Program has in fact contributed to other areas of the Health System (such as the re-construction of the Tuberculosis Program) and made possible the “social control” that suppose to help managing the diverse areas of public health.



Challenges of the provision of medication/ care:

- ✱ **How to guarantee the inclusion of newly registered AIDS cases (keeping more patients enrolled) ?**
 - ✱ Suing the state
 - ✱ Working in research studies and in the media
- ✱ **How to guarantee the coverage by the budget of the acquisition of medication, without discontinuation ?**
 - ✱ Street demonstrations
 - ✱ Lobby
 - ✱ Negotiation with politicians (Vice-Pres., Congressmen)
- ✱ **How to change reality of bad professionals, when they have already been trained ?**
 - ✱ Training again
 - ✱ Hearing their limitation (tool kits? Ability to diagnose? Reference to other care centres?)
- ✱ **How to change adherence/compliance low rates ($\pm$ 50%) ?**
 - ✱ Training PWAs & care givers
 - ✱ Empowering the patients: their treatments in their hands
 - ✱ clarifying treatment aspects and costs to the state.

Brazil as a model: on **what** ?

Fundamentally in the distribution of meds and reduction of cases. The catastrophe previewed in 1992 didn't happen (prevention programs, both carried by the government and the NGOs - separate initiatives - have had some impact).

We would say that the Brazilian National AIDS Program is a success, but the chosen model (WB funding) is not sustainable in the long term, with the same patterns. Centralisation (decisions made in Brasilia) and little division of responsibilities with States and Municipalities make decentralisation difficult. Little observation of the Unified Health System realities (salaries, conditions, invest by stats).

On the other hand, there is no doubt that the loan by the World Bank to fund the activities of the National Program (now National Coordination) was fundamental to allow **real** good practices.

Note that many key technicians at the National Coordination come from the Social Movement (NGOs). This has always made a difference, since the first project.

Effort the? model? No. OK specific model. Needs integrated HC prog. political will centralisation \$

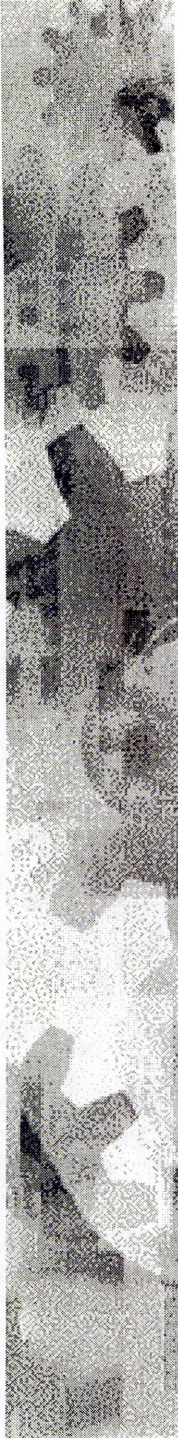
absolutely fundamental



What is so threatening about the Brazilian model?

The possibility of a successful model being a real reference for larger Third World economies (local production threatens interests).

The Welfare state threaten in the neo-liberal world: Universal access in a 3rd W country, when this might not be a reality in central economies (e.g. in how many countries among do homeless people in Western Europe Canada or US get combination therapy for free?)



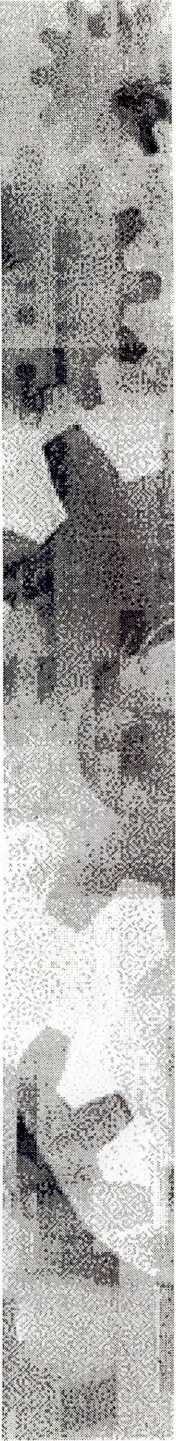
Therefore:

- ✱ We can conclude that the probable success of the Brazilian experience also resides in the fact there were both prevention and care programs being carried on the same time.
- ✱ The fact the Brazilian response be seen as a model internationally does not mean the Brazilian National Program on AIDS can be implemented elsewhere.

We understand we will have to pay a very high price for not having included the AIDS program in the Unified Health System (note this was not possible at the time).

The possibility of funding by the World Bank was based (a) in the fact Brazil was putting also money (90 out of the 250 million US Dollars of the first loan), and (b) the fact it was a loan (will be paid back to the WB and composing financial institutions).

*Note the money to purchase medication has not been included at any time in the Brazilian loan proposal (this is, and we believe **has to be** a national initiative, in our case.*



And the other countries ?

The Brazilian model of local production of medication is certainly a good example for “middle size” economies in the Developing World, such as South Africa, India, Thailand, and certainly some other countries. The fact we have reduced the price of medications in Brazil was due exclusively because the market forces were operating in Brazil, what they do not do in the developed world.

Nevertheless, for smaller economies, with a higher prevalence, other solutions have to be found rapidly. These might include, for example, the Global Fund or access to funding lines by the World Bank and institutions from the financial world to purchase medications. (Problem: sustainability, in a long term. Urgency: maximum)

Distribution, training of health care professionals, as well as development issues have to run parallel to access to medication. Structure of the countries cannot be an issue to justify no distribution.

Is cooperation possible ? **YES !!!**

→ *follow me*

- ✱ Among **governments**: technical cooperation is possible and highly recommended.
 - ✱ South Africa, for example, has been waiting for the promised transfer of technology for production of anti-retrovirals by the Brazilian Government.
 - ✱ Training of health care professional is possible and can be done with relatively low costs.
 - ✱ Trade agreements, e.g. to purchase generic drugs, .
- ✱ Among **community organizations**: what can they do?
 - ✱ Mobilize opinion: GMHC and GPV initiative.
 - ✱ Exchange experiences and work in the mobilization and advocacy issues. TAC and Grupo Pela VIDDA have worked recently together to learn from each others experiences and help accelerate the agreements between the two countries.
 - ✱ Training legal professionals (lawyers) is another issue, to help other countries launch legal procedures to achieve specific legislation and access to treatment.



Finally: what is the role of the foundations and bilateral co-operation agencies ?

The foundations and bilateral co-operation agencies have been playing a key role in the fight against AIDS in Latin America, for example. Nevertheless, there is a growing need and without funds it is not possible to move forward.

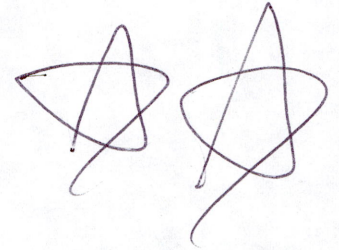
But is how can we move forward ?

I believe the agencies could invest a lot more in the higher impact initiatives, such as advocacy, social mobilization with a “political” connotation.

Without strong social mobilization, there is little chance for long term sustainable actions, e.g. creating stable sources for funding access to care / treatment.

Organisations advocating for treatment might help creating legislation, can monitor the acquisition and distribution of meds, and is able to monitor the funding and the quality of care provided.

Remember:



A sustainable national program has to be accountable and that cannot be without the social control. The organizations of the social movement have to be included in the whole decision making process and conditions have to be provided for their institutional activity. Otherwise, there is very little chance for long term initiatives.

Thank you for your attention.