"A Donor Baby: The Birth of a Community Response" – An Oral History.

The early years of the International HIV/AIDS Alliance (AIDS Alliance)

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Assignment presented in partial fulfilment of the requirements for the degree Master in Philosophy (HIV/AIDS Management) at Stellenbosch University

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April 2014

Declaration

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January 2014

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Abstract

Two parallel processes contributed to the formation of the International HIV/AIDS Alliance (the Alliance) in 1993 – one under the auspices of the World Health Organisation and its "NGO Support Programme" and the other being the coming together in 1991 of a group of donors under the auspices of the Rockerfeller Foundation in an attempt to define a mechanism that would channel funds to community groups in the South. It was a difficult period of the HIV epidemic – communities were struggling to cope with the effects of HIV, science was unable to advance its efforts to find a vaccine and progress into different forms HIV treatment was moving slowly. The two processes came together almost fortuitously, as key individuals were involved one way or another in both processes, and the work that had been done complemented and justified the need to combine energies, resources and creativity into making this mechanism work.

The oral history brings to life some of the discussions and events that took place during the development of the Alliance. It provides insights into what key individuals were thinking, or how they acted during important, and at times frustrating, discussions. Because so little is captured about the conception phase (1991 – 1993), the oral history focusses on capturing the reflections and memories of those who were involved during this period, to ensure that history accurately reflects what happened – or at least offers real and lived perspectives. The case study reviews the start-up phase (1994 – 1996) and provides insights and perspectives into key decisions and the all-important external evaluation, which was a turning point for the organisation. The external evaluation led to and informed the scale-up period (1997 – 2000) and the oral history reflects on a number of key themes that shaped the organisations work and laid the foundation for its next ten years.

Opsomming

Twee parallelle prosesse het bygedra tot die vorming van die Internasionale HIV/AIDS Alliance (The Alliance) in 1993 - een onder die vaandel van die Wêreld Gesondheid Organisasie en die " NGO Support Program " en die ander is die bymekaar kom van 'n groep skenkers onder die coordinatie van die Rockerfeller Foundation in 1991. Hulle het saamgekom in 'n poging om 'n meganisme te definieer wat fondse sal kanaliseer naar gemeenskap groepe in die Suid. Dit was 'n moeilike tyd die MIV-epidemie - gemeenskappe sukkel met die gevolge van MIV , wetenskap was nie in staat om hulle pogings om 'n entstof teen MIV en vooruitgang in behandeling het stadig gevorder.

Die mondelinge geskiedenis bring aan die lewe 'n paar van die besprekings en gebeure wat plaasgevind het tydens die ontwikkeling van die Alliance. Dit bied insig in wat individue dink , of hoe hulle opgetree het tydens belangrik , en by tye frustrerend, besprekings. Omdat daar so min gevang oor die konsepsie (1991 - 1993), fokus die mondelinge geskiedenis op die vaslegging van die refleksies en herinneringe van diegene wat gedurende hierdie tydperk betrokke was. Die gevallestudie gee ‘n oorsig van die begin fase (1994 - 1997) en bied insigte en perspektiewe in belangrike besluite en die eksterne evaluering , wat 'n keerpunt vir die organisasie was. Die eksterne evaluering het gelei tot die “scale up” tydperk (1997 - 2000) en die mondelinge geskiedenis weerspieël op 'n aantal van die belangrikste temas wat die grondslag gelê vir sy volgende tien jaar.

Acknowledgement

I wish to extend my sincere appreciation to the following people who contributed to the completion of this case study. Firstly, the seed was planted by my supervisor Professor Jan du Toit who suggested that I explore and capture the history of an organisation that I work for. This was supported by Alvaro Bermejo – the current Executive Director of the International HIV/AIDS Alliance who encouraged me to capture the reality of the early years of this incredible organisation's history. So as opposed to writing it from a purely historical perspective, it was decided to focus on an oral history, as this would enable others to share and reflect their realities of what was written on paper.

Without the insights of those who were integrally involved, Jeff O'Malley, George Zeidenstein, Jerker Edstrom, Sarah Middleton Lee, and Seth Berkley, the assignment would have been merely theoretical. Their insights and realities brought the history alive and made me realise what an eventful journey the organisation has travelled. And of course the support of friends and colleagues who put up with many hours of isolation or understanding the need to work to deadlines and complete assignments.

1. Background:

The International HIV/AIDS Alliance (the Alliance) is a partnership of linking organisations, country offices, technical support hubs and an international secretariat, working to strengthen community responses to HIV in the developing world. By the time that the idea of the Alliance was incubated in 1991, it was clear that HIV had already had a devastating impact on communities in the developing world. HIV was having broader social and economic impacts on the poorest and most marginalized and was eroding any progress made with regards to reducing poverty (WHO 1992 and Chomba, Piot, 1994 et al).

A group of donors and international partners came together to start a series of discussions on the need to support effective community responses to HIV, and so in 1993 the "International Alliance for Supporting Community Action on AIDS" was created. The Trustees later changed the organisation's name to "The International HIV/AIDS Alliance". The vision was about putting communities at the centre of the response by enabling them to understand and respond to HIV by using a technical and project-based approach through the provision of funds that were supplied by certain governments.

The International HIV/AIDS Alliance celebrated its 20th anniversary in December 2013. Very little is captured about the period 1991 – 1993 with regards to understanding what the motivations were for bringing together this international alliance, or for that matter who initially had the vision for what was to become one of the more successful international non-governmental organisations (NGOs) working in community based responses. Capturing this history is important to ensure that the Alliance takes its rightful place as one of the leading organisations that helped shape and support effective community responses to HIV in the developing world.

"A donor baby – the birth of a community response" is an oral history study that looks at the formative years (1991 – 1993) of the AIDS Alliance to capture and

accurately reflect the beginning of the organisation. It goes on to capture and bring to life key moments in the Alliance's history over its first ten years, from the perspective of five key stakeholders and documented by the pages of history reflected in minutes and reports.

1.1. Research question:

What was the motivation and vision for starting the International HIV/AIDS Alliance?

1.2. Objectives:

- To ascertain what the vision for creating the organisation was and understanding this thought process and motivation?
- To capture the memories and reflections of key individuals in the development and formation of the Alliance?
- To contribute to the institutional memory of the Alliance.

1.3. Periods of history

The conception phase 1991 – 1993

The start up phase 1994 – 1996

The scaling up phase 1997 – 2000

2. Literature review

The Alliance is "a family' – a family of individuals and organisations which is considered to be an influential role-player and shaper in supporting community responses to HIV. As we enter the 30th year of the HIV and AIDS epidemic, it is important that we are able to remember and capture the history of effective responses to a devastating epidemic. Understanding how and why the Alliance was started contributes to the knowledge base defining, developing and shaping community-based response to a public health threat. It was important that the literature review provide an overview of what already exists to bring the history to life, but importantly also identify the gaps in the literature that would help inform and develop strategies to overcome those gaps. A desk review informed

an analysis of existing documents, minutes of meetings and relevant publications. Minutes of meetings and written reports often do not capture the essence or reality of the situation. It was apparent that there was very little information captured in the Alliance archives around the "start up" phase and almost nothing for the "conception phase", particularly around the early discussions, rationale and motivations for starting up the Alliance.

There are meeting reports and minutes of those first meetings, but it was felt that this period should become a greater focus of the oral history. Gathering this information and bringing to life the experiences and realities of individuals involved would contribute first-hand knowledge and bring valuable insights and reflections that would otherwise be lost. The secondary research consisted of the desk review of annual reports for the period minutes of trustee meetings May 1994 – October 1999, and reports of "Alliance supporter meetings" (where these exist).

3. Research methodology:

Oral history is a research methodology process by which an interviewer or historian uses a set of interviewing techniques to allow and support individuals to speak about memories of their past experiences (Field, 2007). However oral history is not just about interviewing. Oral history records stories drawn from living memory and is a cluster of research and life skills constituted through various forms of practice.

Oral history, also known as oral reminiscence, is used to describe a method that uses oral testimony and oral tradition as historical evidence. Oral testimony refers to a narrator's (individual being interviewed) recollection of an event or situation that they have experienced first hand, whereas oral tradition refers to stories or narratives that have been passed on from one generation to another over a period of time (Mooney 2013). Oral testimonies and life histories complement written sources. An oral history therefore involves interviews with

individuals to gain better insights into a particular experience or time when that person was present. It brings history to life through the lived experiences and in the process it allows the history to be preserved and captured. This assignment focuses on oral testimony, and may one day contribute to oral tradition.

According to Field a useful starting point for oral history is that historian capturing the oral history must not forget that they do not simply interview oral sources, but people. In the case of the Alliance I, as the historian, was privileged to be interviewing "family members"– individuals who contributed enormously to the development of an idea and who all felt passionately about what they were doing, and understood why they were doing it. The interviews were used to complement and bring to life written sources identified during the literature review, as a number of narrators were part of the Alliance during the period of this study.

In this relationship it is not the researcher who knows about a particular subject or issue, but the narrator telling their story. It is about understanding their reality and insights and valuing their "expertise" as an important contribution to understanding. These power/knowledge dynamics are important to understanding in the interview process and to ensuring a respectful and cooperative relationship. The principles found in this type of relationship are complementary to some of the values and principles of the International HIV/AIDS Alliance, which focus on partnership, inclusion, acceptance and integrity.

The narrators were interviewed during November 2013 in New York and Brighton, with interviews lasting between 60 and 110 minutes each. The interviews were recorded using an MP4 video format, and then transcribed by a professional company offering these services – Transcript Divas. The transcripts have been integrated throughout the document to add perspectives and reality to moments in time. The transcripts were amended only to ensure consistent language use and flow, and in cases where an acronym was wrong or the name

of institution or person was spelt incorrectly. There was however no change to the core message or idea that the narrator was sharing. The assignment was proofread by a professional proof reader.

3.1. List of narrators

Since there is very little written or captured in the Alliance archives of the period 1991 – 1993, the oral history project interviewed key individuals who were involved in setting up the organisation. Their insight and recollection provided valuable information and contributed to an important part of the Alliance history, as this methodology has the research capacity to deliver new knowledge and provide insights into "mainstream forms of knowledge" (Field, 2007).

The narrators interviewed were identified as a cross-representation of the different stakeholders involved in the establishment of the Alliance – Donors, Trustee, Executive Director and staff. Each narrator brought a specific motivation, perspective and recollection of the early years of the Alliance – and very few, if any, of these early reflections had been captured.

George Zeidenstein: Former President and Chief Executive Officer of the Population Council. George was also a distinguished fellow at the Harvard Centre for Population Studies. He served as the Chair of the Board of Trustees until 2005 and he is now enjoying his retirement.

Jeffrey O'Malley: Is the Division Director of Policy and Strategy for UNICEF. He was the head of the HIV Programme at UNDP prior to his appointment at UNICEF. Jeff was the first Executive Director of the International HIV/AIDS Alliance.

Seth Berkeley: Is the Executive Director of GAVI, and he was also the founding Executive Director of the International AIDS Vaccine Initiative (IAVI). He worked at the Rockerfeller Foundation during the early years of the Alliance history and was instrumental in shaping and defining the early model of the organisation.

Jerker Edstrom: Is now working at the Institute of Development Studies (IDS) at the University of Sussex. He was a programme officer at the Swedish

International Development Agency (SIDA) during the inception phase of the International HIV/AIDS Alliance. He was so impressed by the Alliance that he moved over to the Alliance where he eventually headed up the Field Programmes Department.

Sarah Middleton Lee: Sarah works as a consultant in gender, human rights and HIV/AIDS. She was Sarah Lee when she worked at the Alliance and set up the policy programme before moving on to head up the "inter-regional programme".

While there were many other incredible ad inspirational individuals who were involved in the formative years of the Alliance, it was not possible or practical to interview them all due to time and cost implications. The reflections from the different narrators interviewed and the recollection as told by these narrators does not only contribute to the history of the organisation, but also provides rare insights into key moments of the organisation's history.

3.2. Actual interviews

It is necessary as part of the oral history methodology, to reflect on the context in which the interviews took place. The reason for this is that it could influence the way that the interviews are conducted or the manner in which narrators tell their story. The New York interviews took place at the headquarter offices of UNICEF, where Jeff O'Malley currently works as the Division Director of Policy and Strategy. In hindsight it would have been ideal had the interview venue been more neutral as this would have allowed for more time to set up the interview room, test equipment and prepare for the interview. But since the interviews were taking place in a foreign (and expensive) city, the offer to hold the interviews at the UN building was welcomed. Any UN building can be quite daunting and intimidating with security clearance and security guards watching your every move. Due to a communication breakdown I was unable to gain access until five minutes before the first interview, which was with George. George was accompanied by his wife Sondra and we travelled in the VIP elevator to the 16th floor. This was the first time that I had the opportunity to meet

George, and unfortunately there was little time for small talk, as I had to find the ideal room setting, set up the camera and get George ready for the interview. George took things in his stride.

The second interview was with Jeff O'Malley. I know Jeff from my own work and involvement in HIV as we have worked together previously on joint projects or initiatives. The interview was made a little more stressful when, after 20 minutes of interviewing, I had to ask him to start all over again as I thought I had deleted (as opposed to downloaded) the recording. Jeff, although understandably annoyed, was very professional in the way that he responded. This nervousness was reflected when listening back to the interviews, as my speech impediment was a lot more evident and I realise that there were so many other questions that I should have asked.

The interview with Jerker took place at the offices of the International HIV/AIDS Alliance, and I was better prepared both in terms of time and set-up having had the luxury of the previous interview experiences. The interview with Sarah took place at my home in a more informal and relaxed environment and Seth's interview took place telephonically.

3.3. Interview tools

The methodology specifically does not use structured formal interview tools, but rather uses what is called a story board to elicit responses from the narrator by drawing on direct memory of a particular issue or period. The reason for not using specific questions or a question and answer technique, is to avoid being too prescriptive, leading or influencing the narrator's recollection of that moment in time.

The interviews were issue-focused and covered the three different phases of the Alliance history. Each narrator was sent a storyboard prior to the actual interview to give them to get a better sense of what would be covered during the interview, and assist them in thinking through those periods. The storyboard was

developed after finalising the literature review, which informed a broad outline of the three different phases and highlighted important aspects or moments during the periods that could be elaborated on during the narration.

3.4. Informed consent

Each narrator was asked to complete an informed consent form. The form explained the purpose of the oral history, included sections of the storyboard that would be covered during the interview, and asked the narrator to provide their consent to have parts of their interview used for the final project. A copy of their respective interview film and transcript were also offered to each of the narrators.

None of the narrators were paid for their time. One narrator had accommodation paid for in New York, as he had travelled from up-state to be part of the interview.

3.5. Budget

The costs for the assignment were covered as follows;

Item	Source
Flights – New York	Researcher
Hotel Accommodation (NY) – Researcher	AIDS Alliance
Hotel Accommodation – Narrator	Researcher
Interview equipment	Borrowed
Transcript Divas	Researcher
Editor	Researcher

4. The conception phase (1991 – 1993)

"What brought them together is a common belief that community responses mattered, and a common belief that their own systems and WHO systems weren't set up properly to partner with or support those responses." Jeff O'Malley

4.1. A changing global landscape:

HIV was spreading its ravages around the world and a lethargic world was eventually galvanised into action as a gradual and slow international effort came about in 1987, when the World Health Organisation set up the special programme on HIV/AIDS – this became known as the Global Programme on AIDS (GPA). This new programme was to be an initiative to coordinate international action on AIDS and to support developing countries in their response. The late Jonathan Mann was appointed to run the programme. Part of this initiative was to set up a multi-donor trust fund – jointly administered by WHO and UNDP – to support ministries of health in developing countries to set up AIDS programmes and responses. "WHO used to send its staff and consultants to meet with the ministries of health to try and convince them to do stuff about AIDS, and that there would be some money to back them up, as an incentive" stated Jeff O'Malley.

He continued "and in that already delayed response, which was completely organised around supporting ministries of health, but the ministries of health were not the actors actually doing stuff on AIDS in almost any country, rich or poor. The people who were actually doing stuff on AIDS were people living with HIV and their partners and friends and families, and some community groups." The incentive part that was offered to developing countries' governments was access to this jointly administered trust fund, which according to Jeff was the first significant international development assistance, or linked financing for AIDS responses in developing countries.

In 1988 during the International Conference on AIDS in Stockholm, another Canadian, Ken Morrison, organised a meeting of community groups involved in HIV. Jeff recalls that most of the groups were Northern-based organisations –

The Terence Higgins Trust (UK), Gay Men's Health Crisis (New York), Austria AIDS Hilfe and a few others – who came together to talk about the need to support each other and learn from one another during these challenging times. At the same time Jeff had started writing to the WHO asking them what they were doing to support community groups in developing countries, "and one thing led to another, and WHO actually first supported the organisation of a meeting of NGOs, including developing country groups including AIDS-specific groups and church groups such as the Salvation Army".

The meeting was called "Opportunities for Solidarity" and Jeff was offered a consultancy (which eventually became a staff position, under the supervision of Bob Grose) at the WHO to develop a strategy to support NGOs in the developing world. Jeff administered a two-year pilot programme that had some valuable lessons in terms of what the WHO could and could not do, "it became clear from that pilot, certainly for me, that WHO could do some things, some useful things, especially because of its political clout with ministries. But it was not well established to support community groups financially or technically, and it wasn't clear to me and other colleagues at the WHO, about WHOs ability to really have an impact at a community level". It appears that the scepticism was well founded as an ongoing conflict between Jonathan Mann, who was heading up the GPA and WHO Director General Hiroshi Nakajima had brought internal relations to an all-time low, and Mann was asked to resign in 1991. This clash was related to differing perspectives on what the WHO should be doing around HIV.

This is what led to discussions, initiated by the WHO (Bob Grose) and a group of donors, who came together to start talking about what the lessons were from the WHO pilot. Jeff indicated that the experience of what the WHO managed and did not manage to do with regards to providing support to NGOs in the developing world, was a catalyst in starting a discussion about how this could be done collectively "And even if John Mann was at WHO, some of that would have happened, it was probably accelerated because there was a sense that with John leaving, there was a number of external stakeholders and donor agencies who

believed that Nakajima was not very committed to the AIDS response in general. So there was this sort of inherent challenge of WHO working with NGOs linked to the kinds of new challenge that the big champion of AIDS working in WHO was pushed out".

Jeff continues, "There were discussions of WHO staff, including my boss Bob Grose and some donor agency people saying 'what have we learned from the WHO pilot project or from our own experience?' What brought them together is a common belief that community responses mattered, and a common belief that their own systems and WHO systems weren't set up properly to partner with or support those responses".

At about the same time, the Rockerfeller Foundation, together with International Family Health (IFH), set up a steering committee to specifically look at developing a mechanism to support NGOs in the developing world. Seth Berkley, one of the co-chairs of the committee said, "we wanted to figure out whether there was a more effective way to engage NGOs in HIV, we knew and saw the limitations of government programmes". The steering committee was tasked with carrying out work to establish the need for a new initiative, to develop a conceptual approach to respond to this need and test the feasibility of working with local leadership to establish effective community responses. Seth continues, "there was an idea from David Navarro that we would make it so simple that it would operate as a franchise model, but at the time there was no drugs and prevention was important. We wanted to get money out to NGOs. It was atypical for the Rockerfeller Foundation to be involved in this, but people felt it was important."

It appears that these two processes – one led by Bob Grose and the other under the auspices of the Rockerfeller foundation – were happening in parallel and eventually came together through similar people being involved in both processes. "I do not recall the two processes being linked, but because there was so much similarity, it was inevitable that they would come together. It was clear

that we needed a simple mechanism that would get money to community groups, and it just had to happen" said Seth.

4.2. The Rockerfeller connection

In August 1991, a group of eleven bilateral agencies[1] met at the initiative of the Rockerfeller Foundation to discuss what more could be done to support AIDS prevention, care and community support work by local and national non governmental organisations. The group set up an interim steering group which was co-chaired by Seth Berkley and Jane Hughes.

4.2.1. "The HIV/AIDS NGO Support Programme"

The donors wanted to get a better sense of the gaps in existing support to NGOs in the developing world, and commissioned a five-country study known as the "The HIV/AIDS NGO Support Programme". A group of consultants, hired by the Nuffield Institute for Health Services Studies (Anne Buve, Danielle Candau, Wendy Cook, Doris D'Cruz-Grote, Chris Elias, El Hadj Amadou Sy, Ruben Grania, Aimee Martin, Malcolm Potts, Geeta Rao Gupta, Frants Staugaard, Irmela Schnee and Eka Esu Williams) were appointed to undertake a study in Egypt, Cote d'Ivoire, India (Maharashtra State), Mexico and Tanzania.

The design of the study had been informed by a strong consensus around three broad goals:

- To enable people to reduce their risk of acquiring HIV/AIDS and other STDs;
- To enable more people to cope with living with HIV/AIDS; and
- To enable communities to have an increased capacity to cope with the causes of and consequences of HIV/AIDS.

[1] Canadian International Development Agency (CIDA), the Commission of European Communities (CEC), the Dutch Ministry of Foreign Affairs, the French Ministry of Cooperation, the German Cooperation and Technical Assistance Agency (GTZ), the OECD, the UK Overseas Development Administration (ODA), the Rockerfeller Foundation, the Swedish Development Agency (SIDA), the US Agency for International Development (USAID) and the World Health Organisation/Global Programme on AIDS (GPA)

There was a sense that the study had to be conducted in a variety of settings that focused on social, geographical and economic contexts to determine the financial, technical and managerial needs of groups working outside of government.

The study had specific objectives, which focused on:

- Reviewing the current activities of NGOs in HIV prevention, care and community support;
- Assess the potential for an expanded role for NGOs in this area;
- Identify the support required for NGOs to reach their full potential;
- Review the existing in-country mechanisms for international assistance; and
- Consider alternative mechanisms for assistance to local groups.

The design of "the NGO HIV/AIDS Support Programme" consisted of a team of at least two consultants visiting each of the five countries, to carry out focus group discussions and interviews with a wide range of stakeholders. A larger emphasis and focus was placed on those stakeholders who were working outside of government, as this was an area that the donors wanted to better understand to help them provide the appropriate support. The country teams also visited representatives of various government departments (including National AIDS Programmes) and in-country donor agencies.

The analysis identified a number of commonalities between the NGO responses in the five countries and highlighted a number of key opportunities. Although most of the NGO activities focused on education and raising awareness, there were examples of working with marginalized groups such as sex workers, gay men and people who use drugs. The NGOs were able to reach these groups in a way which government programmes could not as many of these groups or practices were criminalized. In addition NGOs could implement programmes with hard to reach populations directly, such as providing condoms and lubrication to

gay men in Mexico, whereas government-supported programmes would avoid this due to political sensitivities.

There were also a number of challenges identified by the consultants. These challenges were related to organisational planning, collaboration and coordination with other stakeholders (NGO and government) and programming issues (planning, reach, and evaluation). The framework and outline of a programme of support was starting to take shape, as the NGOs were able to articulate their needs around funding and other flexible means of support. These focused around three broad areas:

- Technical assistance and more funding, particularly in the form of "seed funding" to support new and growing community groups;
- Training and capacity-building that focussed on issues such as being better informed and updated to respond to HIV more effectively; proposal writing, strategic planning, work planning, management information systems, monitoring and evaluation systems;
- Management, administration and organisational development issues.

The study found that international assistance to indigenous NGOs was channelled through one of three mechanisms. These mechanisms were NGOs receiving funding directly from their own governments (mostly through the Ministry of Health), or direct support from international donor agencies – usually multilateral/bilateral agencies, or multilateral support channelled through NGOs that work internationally. The NGOs that were receiving support directly from their governments felt that it was often a very difficult and frustrating process whereby bureaucratic processes or funding restrictions on types of programming were cited as challenges. In addition, NGOs felt that they were not seen as equal partners in implementing programmes, but rather as a less expensive, implementing vehicle for government programmes.

Receiving funding directly from donor agencies also had its challenges. NGOs felt that there was often a lack of coordination in priorities and programmes across and within donor agencies. Funding sources were seen as unpredictable and volatile as these often changed according to donor priorities. It was felt that funding disadvantaged smaller NGOs and it was often the bigger, personality-driven NGOs that were able to access funding, as they had the capacity and systems to develop sound funding proposals and meet demanding report requirements. Perhaps one of the most important outcomes of the five- country study was the recognition that the existing funding mechanisms did not address the complex and varied needs of NGOs in the areas of financial, technical and managerial support. It was felt that the lack of recognition and understanding for this more comprehensive approach (funding and technical support) was a primary reason why there had not yet been a more effective community response to HIV.

The report proposed certain elements that would be required for an effective mechanism that could provide funding and technical support to community-based organisations. The mechanism would require the ability to:

- Support innovation and experimentation, as well as proven interventions;
- Remain flexible and allow for variation according to local needs;
- Entail a minimum amount of bureaucracy, including the rapid disbursement of funds, by having simplified proposal and accounting systems;
- Encourage capacity building and provide or identify appropriate technical assistance; and
- Include an evaluation component in all programmes.

4.3. A focus on HIV prevention

Most of the official HIV programmes that had been developed at the time, were focussed on HIV prevention work, "these were structured by development assistants, public health officials, specialists, technocrats, bureaucrats in dialogue with politicians, and the obvious arguments for spending money on AIDS was 'look, if we can spend a small amount of money to prevent its transmission, we'll save more money in the long run.' Because when money gets appropriated or allocated for programmes, it is always for a reason, and the reason that the technocrats could sell or the reason that people thought was important, was HIV prevention."

Jeff admits that there was valid reason for this false dichotomy. "I mean there was nothing that worked all that well. Bactrim prophylaxis was around already and had been shown to extend life for a bit, and psychosocial support was starting. But, it is not hard I think for you to imagine some bureaucrats and politicians having a discussion saying 'well why spend money on somebody for a few months or six months? Clearly the better investment, the better value for money is to stop the person getting infected in the first place, right?' It is really easy to imagine how it happened. And one of the reasons it's easy to imagine how that happened is because those discussions happened without people with HIV, without community people. That is what happens when you have an abstract discussion far away from an issue".

According to Jeff some of the people involved in the discussions that led to the establishment of the Alliance, felt that it was important to channel resources to care and support. Up until that time most of the international efforts, including the WHO/GPA, were focussed on HIV prevention. There was a sense that there was a moral obligation to do so, but also because there was already a recognition that if HIV prevention was going to be effective, HIV care could not be ignored. "So I think there were some thoughtful WHO and donor officials who said that our own restrictions and rules are a problem, not just because they don't allow

us to support community groups, but they are also a problem because they don't allow us to support care".

There was recognition and explicit discussion in the start-up phase that one of the advantages of setting up the Alliance, in addition to getting aid to community groups, was that this was also a way in which resources could be used to support care.

4.4. Identifying the leadership

Jeff was initially approached early in 1993 to ascertain his interest in being involved in the new initiative, but at the time his partner Chris was ill from AIDS-related complications, ultimately dying, and Jeff felt it was the wrong time to join the organisation. The steering committee then made offers to two different people, Chris Elias (who turned them down) and then David Wilson. According to Seth, David Wilson was about to take up a position, "discussions went quite far with David, so I was very disappointed when he turned us down". Chris Elias went on to become the CEO of PATH and is now the President of the Global Development Programme at the Gates Foundation while David Wilson is the Director of the Global HIV Programme at the World Bank.

However, in October 1993 Jeff was approached again by the Rockerfeller Foundation, "they were trying to identify an Executive Director and they wanted to have some meetings with potential candidates. They called me within a week of my partner Chris dying, and if they had called me the week before, I would have said no. I remember that Chris's parents were still with us in Montreal as they had come up from British Columbia. And I put on a suit and tie and flew down to New York where I met Jane Hughes and Seth Berkley, who were co-managing this at Rockerfeller. It was not really clear whether it was a meeting or a job interview or what it was, but it was a discussion. They called me up shortly after and asked me whether I would meet the person who was going to chair this thing, and his name was George Zeidenstein. He was based at Harvard then,

which is also where I had been working. I flew down to Boston and I had breakfast with George, and following that I guess that George talked to Jane and Seth and one of them, I don't know who, contacted me and said that they wanted me to take this role on, was I willing to do it?" Jeff recalled.

He went on, "and the timing was perfect. As I said, I had taken a leave from my job to go to Canada as Chris was sick, and I had to decide whether I was going to go back to my job in Boston or do something else. I had just lost my partner, and thought – what the hell! I had spent much of the last five years being an activist saying that the world needed to do something on this, and I was being given a chance to work full-time on shaping an initiative that was dedicated to do exactly what I was saying the world needed to do."

He reflects a while and then continues, "I mean this all moved very, very quickly, and then the first week of December we had our founding meeting. I went from not knowing whether I was going to move back to Boston, what I was going to do, talking to George, talking to Jane and Seth and being asked and agreeing to take on this new role. I showed up at the Paris meeting as the Executive Director designate of this new organisation, and that was the first week of December 1993".

Jeff says that he found the offer very attractive as, "they were very clear on the one hand about the mission, but on the other hand that they wanted to hire someone like me to put flesh on the bones, to shape the details, so I also felt I was being given a responsibility for a mission, but I was also being given the authority to shape the details". He went on to say that, "it was also just the perfect time in my life in all sorts of ways, again with Chris dying, with having learned from Jonathan (Mann) but not sure if I wanted to go back and work for him again, and basically being invited. I mean this group said 'look, we are going to give you some money, we are going to connect you to some connected people more senior than you, who can help you open doors politically, to set up an

organisation to do what you have been fighting for, for five years', so who would not say yes?"

4.4.1. The Board of Trustees

The vision for the composition of the Board of Trustees had already been identified by the time Jeff accepted the offer to become the Executive Director, "I think fortunately there was a vision of the board already, and that vision of the board partly preceded me. I was 31 years old, which in terms of heading up a multi-donor international NGO, I was young. Although I had the relevant background I was inexperienced, and it was important that there was a board that balanced me".

George Zeidenstein, spoke about identifying and selecting the trustees, "I knew these people, and I knew them well. What can I say about them? They were all what I regarded as very solid international development people, basically social scientists, except for Koye (Ransome-Kuti) who was a physician but who had some of the broader interests and caring qualities that I do not normally associate with physicians, unless they are sort of special – and Koye was certainly a very special person. So, they fitted the bill that would constitute an international board, and a knowledgeable international board about all the things that are critical to get going with an organisation that had the kind of objectives that we had in the Alliance".

Jeff shared the vision of having a small Board of Trustees that would be affordable and effective, "but a board of senior people who would bring political gravitas, wisdom and maturity to my immaturity and lack of wisdom, and I say that in all sincerity. I was bringing activism and passion and enthusiasm and energy, but they were bringing experience and connections!" he remarked.

Sarah Middleton Lee's recollects her first encounter with the Trustees, "I remember walking in and with all due respect, it was really like a group of elders.

There was this amazing quite senior – both in age and status – group of people around the table. It was very formal. They were lovely to me personally but it was quite formal and it was all very serious. They were engaged and interested in what we were going to do. Even with them, not many of them had direct experience related to HIV so I do not think any of us knew entirely what we were doing, including them! But they did have extensive experience from the field, so we all muddled along together."

George was described as an effective working chair as he was actively involved in the early years of the Alliance, and was paid a minimal honorarium as a working chair. He said that it was important for him to be actively involved in the development of the organisation. "I think because there were not any models around, at least not in the field of HIV and AIDS work, and Jeff was quite young and very exciting and excited. I think that all the people who had been instrumental in pulling it all together and I agreed that for a period one really needed a kind of chair and to a certain extent a board to be working like staff"

The first Board of Trustees was listed as follows:

Kaval Gulhati, India. A senior fellow at the Centre for Policy Research and founder of the Centre for Development and Population Activities;
Joan Lestor, United Kingdom. A Member of Parliament;
OliKoye Ransome-Kuti, Nigeria. Former Minister of Health of Nigeria;
Fatou Sow, Senegal. Chair, Department of Social Sciences, University of Dakar;
Carl Wahren, Sweden. Head, AID Management Division, Development Cooperation Directorate, OECD Former Secretary General of the International Planned Parenthood Federation; and
George Zeidenstein, United States of America. Distinguished Fellow, Harvard Centre for Population and Development Studies and former President and Chief Executive Office at the Population Council.

The chair and incoming Executive Director were clear that they wanted half the Board to be from developing countries. And before Jeff could be appointed the Board had to incorporate itself to become a legal entity that could employ staff. Up until that time International Family Health was acting as the secretariat to this new initiative. The decision about where to incorporate the new organisation was informed by national legal requirements related to the number and composition of trustees required for registration.

The initial idea was to set up the Alliance secretariat in France, but on further investigation it became apparent that to register in France, the majority of trustees of a non-profit had to be French nationals. “We knew that we had to be in the European Union because we wanted to access European Commission money, and in order to do that you had to be present in the EU,” said Jeff. But with France out of the question, they had to find another country that would allow them to have the Board that they wanted, “we found three countries; Greece, the Netherlands and Britain that allowed boards that were non-nationals. Neither Greece nor the Netherlands offered us any money and the UK offered us some, so we ended up deciding to go to Britain based on a quirk of company registration law, and that would allow us to have the board of directors we wanted,” said Jeff.

Although the Board of Trustees was established at a special meeting on Wednesday 08 December 1993, following the supporters meeting in Paris, the Alliance was only registered with the Companies House in January 1994 and the trustees had their first meeting in May 1994.

4.5. First annual supporters meeting:

On the 8 and 9 December 1993 at L’Institut des Cordeliers in Paris, France, “the International Alliance Supporting Community Action on AIDS” was launched as a “multilateral, nongovernmental organisation, with a commitment to mobilising

and sustaining financial participation from governmental, foundation and corporate donor" (meeting report, 1993).

George Zeiderman, became the organisation's first Chair of Trustees and said about the meeting "France acted as host, and we had this quite extraordinary kind of meeting. The food was unbelievably good and we occupied this quite gorgeous old room in the Sorbonne that had huge oil portraits all around, of well know French intellectuals. That is where we sat, and the main thing that we were talking about was well, we've now got this thing organised, how are we going to move forward and where is the money going to come from?"

Donors pledged $US 5 million to launch the new organisation, and those who were not able to give financial contributions, pledged technical assistance, programmatic guidance and ongoing advice as the organisation got started.

Jeff O'Malley reflected on the outcome "I was also fortunately naïve enough to think that it went well, because if I knew then what I know now, I would have taken the promises with a grain of salt. I would have said that this is nowhere near enough money to start up. I mean we ended up with a start up grant from the Rockerfeller that I think was US$ 600 000 or 800 000".

The organisation started with a small budget, no staff, no clarity on where it was going to be registered, apart from knowing that it had to be in an EU country as this was a prerequisite for EU funding. "So we started with a pretty small budget and very little clarity on rules, virtually nothing in terms of multiyear commitment, and I was packing up my life and moving to another country. We were starting up an organisation and I was going to be recruiting people on a remarkably flimsy foundation," remarked Jeff.

The venue of the supporters meeting also stayed with Jeff, "the room we were in was beautiful, which was also a little strange. But, the strangeness was par for the course in the AIDS World at the time. Moving from Elizabeth Taylor and

celebrity type things for fundraising, to people with Karposi Sarcoma (KS) and PCP (Pneumocystis Carinii Pneumonia) and not getting into hospitals because hospitals simply would not let them in; it was a very weird world, the AIDS world, and these strange juxtapositions were part of that weird AIDS world at the time".

It was agreed at the meeting, that the new organisation "would provide a cost-effective and rapid response to the HIV pandemic, to save lives and to reduce the suffering of those already infected with HIV" (meeting report). The central strategy was the identification or establishment of national groups (linking organisations) who would be provided with financial and technical support so that they in turn could become local providers of financial and technical support. The meeting in addition, agreed to the following roles for linking organisations.

- Helping organisations already engaged in HIV/AIDS prevention, care and community support to expand and scale up their work;
- Assisting smaller community organisations to develop their managerial and technical skills; and
- Reaching out to a wide variety of private sector groups not yet engaged in the prevention and management of the epidemic.

It was during this first supporters meeting that the name was changed from "The International Alliance Supporting Community Action on AIDS" to "The International HIV/AIDS Alliance" as the former was considered too long and difficult to remember.

4.6. "The proposal for support"

In preparation of the first annual supporters meeting, Cliff Lenton, who was a consultant in population and family planning, was hired to pull together a three-year proposal that would be presented to donors for their consideration. Jeff recalls, "I did not just show up at the meeting. I did some work with a consultant who had been hired. It was essentially a proposal, like a funding proposal for the set up of this new organisation, and at the founding meeting the findings from

the five country studies and pilot project were presented. Cliff did the first writing of that proposal, but then I was brought on board and did some editing and changing in consultation with George."

It was decided that the proposal for support would benefit from field experience, and the Interim Steering Committee made a decision to identify two different countries. The two countries chosen were Burkina Faso and the Philippines as they provided an opportunity to compare two very different scenarios and realities in terms of epidemiology, level of civil society mobilisation, capacity of NGOs and level of support from the national government.

The purpose of including field experience was to define and develop a model approach to the establishment of an "Alliance presence" in country. A coordinated approach involving consultants and pre-consultation with relevant stakeholders in country was developed and implemented. This included communication with relevant civil society stakeholders to introduce the purpose of the Alliance, and initial discussions with government stakeholders to ascertain the acceptability of an Alliance presence in country. The remit of the teams was quite clear – and that was to find out whether there was an existing structure to assume the tasks of an Alliance Linking Organisation (LO), and if there was not such a structure, the team had to explore what new structure would be feasible and acceptable.

4.6.1. Overview of country study outcomes

Burkina Faso: By 1993 a number of NGOs had been established to respond to HIV. The government had set up an NGO Coordination Office to monitor NGO activities, and the NGOs had created a permanent secretariat to support NGO networking and mobilise international resources for grass-roots community mobilization. At the time NGOs were struggling to secure financial resources to carry out their activities, and financial support from the government was non-existent, as its HIV programme was short of funds and the government did not

have the capacity to support or mobilise NGOs. What the Alliance was offering – financial resources with technical support and organisational development – was therefore attractive to NGOs and to the government. With the support of the country consultants, a committee comprising various civil society sectors was elected by broader civil society to develop and manage this new programme, which was placed within the permanent secretariat for NGOs. It was known as the Comité du Programme National d'Appui au Secteur Prive pou la Lutte Contre le SIDA au Burkina Faso. The purpose of the committee was to provide financial and technical support to community based organisations, through a request for proposals.

An initial start-up grant of $20 000 was provided to the committee, and within the first three months it had developed policy guidelines and criteria for the selection of NGO projects. It received 45 applications after its first call for proposals, and was able to fund six, with the hope that there would be continued funding from the Alliance after the pilot project was over.

The Philippines: The HIV epidemic was in its early stages in the country and mostly concentrated among certain population groups, such as men who have sex with men (MSM). There were more than 30 NGOs who were active in HIV prevention activities. The government, while supportive of NGOs, was not able to provide sufficient resources to the NGOs and many NGO projects were short-term, developed in isolation and lacked a strategic focus. These challenges were compounded by the fact that NGOs did not have access to flexible funding or appropriate and timely technical support.

The Philippines HIV/AIDS Support Programme (PHANSuP), was established in June 1993. Once again, with the support of the Alliance consultants, a committee was established to identify the necessary administrative and financial procedures to provide financial support to community-based organisations. PHANSuP had awarded three grants to NGOs working outside Manila with the start-up grant provided by the interim steering committee. The organisation had also hired a

coordinator and developed a three-year work plan, which they hoped would be funded by the steering committee.

The two pilots had laid a strong foundation for what was to be presented to the donors at the annual supporters meeting. It demonstrated that local NGOs were willing and able to make considerable efforts to access funding to support projects that were focused on community-based actions and needs. The pilots also demonstrated that it was possible to establish linking organisations quickly and that these organisations were able to work within certain guidelines to develop funding criteria and provide technical support to community-based organisations. While there were still many unanswered questions around developing clearer guidelines and criteria for accessing funding, the minimum legal, financial and administrative requirements needed to receive funding; and issues around monitoring and reporting, the Alliance had been formed and was developing.

4.6.2. Donor pledges:

Donor	Pledge	Conditions
Commission of the European Union	ECU 2 million	Support Alliances core activities for two years. To provide development funds to start up Alliance LOs in five countries and to provide three-year support to PHANSuP.
The French Ministry of Cooperation	FF 5 million for the first year of Alliance work	Flexible funding to be used for core and country activities, particularly priority countries of the Ministry
Rockerfeller Foundation	US$ 350 000	Flexible funding
Swedish International Development Agency (SIDA)	SK 1 million per year over three years	Unrestricted grant
Overseas Development Administration – UK	GBP 500 000 over three years	Unrestricted core grant
United States Agency for International Development – USAID	US$ 200 000 per year over three years	Unrestricted core grant

World Health Organisation – Global Programme on AIDS		Political support through National AIDS Programmes and the provision of technical support to Alliance and LOs

There was unanimous agreement from participants at the meeting about the need for this new mechanism and the importance of it being able to strengthen and enhance the non-governmental response to HIV. There was a sense that the two years of planning work had prepared the organisation to expand into at least 14 countries over the coming three years. The supporters, perhaps caught up in the euphoria of the moment, encouraged the Alliance to be as flexible and pragmatic as possible and ensure that fixed patterns of working were minimised when providing support.

George requested the donors to process their donations as quickly as possible, as the organisation had need for these funds to get up and running.

5. The start-up phase (1994 – 1996)

"This grand plan to set up linking organisations with a very coherent set of visions and values as well, which were very attractive to us as a donor, because it was clear what the business model was, what the job at hand was. Something like this did not exist – an organisation to support national responses through building national leadership that was inclusive and trying to unite a sector around the issues of HIV." Jerker Edstrom (formerly of SIDA).

5.1. The impact of the WHO

The Alliance was set up to focus on the community-based response to HIV, while the WHO/GPA had the mandate to focus on national governments. With support from WHO/GPA, countries were encouraged to formulate short-term (3 – 6 months' duration) plans of action, followed by 3 – 5 year medium term plans (MTPs) that were to be reformulated based on periodic evaluations. With financial support provided by WHO/GPA and other development agencies, countries ended up with a National AIDS Programme (NAP), which was also supposed to have an inclusive, aligned and coordinated framework for stakeholders working on HIV.

However, O'Malley and Tarantola, developed a paper entitled "The Epidemic, the Response and the Alliance", which was presented to the Alliance Trustees at the first Trustees' meeting in May 1994. The paper highlighted the fact that although the approach to the development of the NAPs was sound, these programs were flawed in at least three ways:

1. The programs focused strongly on ministries of health, who in many instances have limited influence within government and operate on minimal budgets. In addition, the ministries were unable to galvanise broad-based support, which resulted in limited or no buy-in and consultation from other government ministries or civil society organisations.
2. Many governments were withholding services to marginalized groups (such as sex workers, homosexual men and intravenous drug users), as often these groups were not even recognized within programmes. This resulted in

funding being misdirected to blood transfusion safety schemes, mass unspecified and misdirected information campaigns, and central program management schemes.

3. Government programmes were overly centralized and operational and financial decentralization and delegation of authority were not part of the programs.

By 1993 many countries had completed their first MTP and were required to develop programs on the "second generation MTPs". These called for a multi-stage, enlarged consultative process, but very few countries had undertaken a broad-based consultative process. WHO/GPA global strategy document failed to set out a strategy to minimise individual and collective vulnerability to HIV induced by cultural, social or economic factors.

The ability of the WHO/GPA to coordinate the global AIDS response was being questioned, and according to Jeff a culmination of events took place that may have impacted on the Alliance's ability to be bold and ambitious. "A very crucial thing happened between December 1993 and May 1994 and we had not fully realized its impact. WHO was largely discredited as an international convener of support to AIDS in developing countries." While the WHO was being discredited there were donors who did not want to give their money to WHO/GPA, but who wanted to support HIV work. Perhaps the AIDS Alliance had not capitalised on this trend sufficiently, and had assumed that the founding donors would simply meet their financial commitments made to the Alliance.

5.2. Ambition approved, the model defined?

At the first Trustees' meeting in April 1994, the secretariat presented a budget and work plan to work in 14 or 22 countries – either option quite ambitious for a new start-up organisation. The Trustees eventually approved the budget to work in 14 countries, but O'Malley remains undecided, "looking back I still have not decided whether we were too ambitious or not ambitious enough. There was no

mechanism to support community action on AIDS in developing countries. It was 1994. It was over a decade into the AIDS response. There was nothing!"

He went on to say, "There were some foundations who gave money here and there. I shouldn't have said that there was nothing, but there was nothing systematic, and the stuff that happened was remarkably piecemeal, small scale. The need was enormous".

The Board approved Burkina Faso and the Philippines as the first two linking organisations, although both Jeff and George recall that there was a lot of debate as to where to start and why, "the African AIDS epidemic at the time was a central African and West African epidemic. Zaire was seen as the epicentre and places like Zimbabwe were seen as virtually free of HIV." He went on to reflect on the Philippines, "which turned out until very recently to have not much of an HIV epidemic, but at that time the Philippines had a massive commercial sex industry associated with the American military presence, and there was every reason to think that if there was going to be a big epidemic in Asia, it may well start in the Philippines".

The modality of how the Alliance would work was informed by the five-county study, but the Trustees also took the discussions (and the model) one step further. The Trustees decided that it would not only be the Alliance that would be an intermediary, but would instead focus on a model of either identifying or supporting intermediaries in every country. Jeff felt that this was not necessarily the vision that the donors had, and although the Trustees' vision did not contradict the donors' vision, the Trustees were trying to get to the question of how the Alliance would connect to community groups.

The decision was therefore to systematically create another layer called linking organisations. Jeff was clear about the discussion, "they would not be country offices of the Alliance, but independent organisations. They would be southern indigenous organisations (some set up by the Alliance). They would be southern

NGOs setting up to channel money to community groups locally, but they would also play a role in building networks and sharing experiences". The idea was that these linking organisations would serve as a national voice for communities within these countries, "we had this model that Linking Organisations would be indigenous and would therefore be able to speak to indigenous actors, and I think all of us, or a lot of us, thought that was important. Just as my own vision of how the NGOs, civil society movement on anything, should develop, where I saw a role for northern groups was in technical cooperation and solidarity, not in running things in the south" said Jeff.

Another international event had an impact on the Alliance's growth and expansion, "a decision was made to create something called UNAIDS just as we were starting in 1994, and it took the air out of our balloon", sighed Jeff. "The biggest argument that we had was that WHO was working with governments and health ministries, they do not get prevention and care together, they don't get community, they don't get multi-sectoral. We're the complement to WHO! But, then there was the decision and with WHO largely out of the AIDS business, a new UN organisation, multi-sectoral, lots of rhetoric of community, multiagency, new way of working. UNAIDS got a lot of political attention and got a lot of money very quickly and more than a few people said 'well, do we even need the Alliance now that we have got UNAIDS?'"

5.3. A donor perspective

Some of the donors clearly still saw the need for an organisation such as the Alliance. A representative of one the founding donors, Jerker Edstrom, who was representing the Swedish International Development Agency (SIDA) at the time, said of his first meeting, "it was an amazing meeting, very dynamic and very inspiring. This model had been tested in the Philippines setting up PHANSuP, this grand plan to set up linking organisations with a very coherent set of visions and values as well, which were very attractive to us as a donor, because it was clear what the business model was, what the job at hand was. Something like this did not exist – an organisation to support national responses through building

national leadership that was inclusive and trying to unite a sector around the issues of HIV".

The impact of those initial impressions was not lost on Jerker, and he said that he was completely enamoured with the Alliance, "being young and at that stage, still very excited about those kinds of developments it did not take long before I jumped ship". Jerker eventually joined the Alliance in May 1995, and according to him, "SIDA did feel as if the Alliance was offering something unique, something that was not on offer elsewhere. What the Alliance was offering – a clear vision, business model and values around local ownership – was very democratic and a bottom-up philosophy which fitted quite well with the Swedish perspective on what development should be about, particularly in the NGO sector".

5.4. A differing vision

With the creation of UNAIDS and what was apparently becoming a stronger disjuncture in understanding of the model between the donors and the Alliance secretariat, the organisation ended up only focusing on 12 countries, and establishing in eight by the end of 1996. These eight were Morocco, Senegal, Burkina Faso, Ecuador, Sri Lanka, the Philippines, Cambodia and Bangladesh. According to Jerker, "the model was for some of the donors this cost efficient model that would get lots of money out to lots of places quickly, and that was the yardstick by which our efficiency was measured."

Jerker feels that the cracks were beginning to show, as there were differing visions as to what the model was or should be, "those first early years were rapid learning curves for all of us. And don't forget that Jeff came from a GPA, HIV specialist as well as an activist background. I came from a development background with participatory approaches and an interest in sexual health and HIV, and we had a much more in-depth engagement with the epidemic than did any of the donors frankly. They were interested in numbers and blue prints, and we were interested in how we were going to change Senegal? How can we really

empower people to deal with this epidemic? That was two totally different understandings of what the project was about, but if you had actually looked at the vision and values and what the Alliance proposed to do, our understanding was much closer to reality of what it takes."

The initial target was to establish and support NGO mechanisms in 14 countries with an anticipated funding level of approximately US$ 21 million in unrestricted funds. However what transpired was that only 10% of the anticipated funding was pledged and further fundraising resulted in an additional US$ 9 million being raised over the three-year period – but, more than half of the funding was restricted and many of these restrictions resulted in deviations from the original plans and vision. Jeff wrote in a case study that the Alliance's most significant mistake in its first two years was its failure to convene stakeholders to agree a new business plan and new targets in light of real commitments and restrictions rather than the original projections and hopes. (O'Malley, 2000).

5.5. A disappointing supporters meeting

The third supporters' meeting was held in November 1995 at the offices of the newly created UNAIDS. Seven donor representatives were present, but three sent their apologies, which led to a robust discussion among the Trustees at its next Board meeting in April 1996 as to whether the donors were taking the Alliance seriously.

The Alliance had by the time of the supporter meeting, mobilised and supported over 150 local NGOs and CBOs to work on HIV in a variety of settings. The model was also well on its way to being developed – building the capacity of community based organisations through financial and technical support. The Alliance had six Linking Organisations (Philippines, Bangladesh, Sri Lanka, Burkina Faso, Senegal and Morocco) which had set up systems and processes to support community-based organisations.

The supporters meeting was informed that the six Linking Organisations had all been successful at (Meeting Report, November 1995):

- Mobilising new NGOs to get involved in HIV;
- Encouraging NGOs to think of their programmes within the context of the overall national response;
- Helping NGOs build on their existing strengths; and
- Fostering collaboration and exchange among NGOs and between NGOs and governments.

The Alliance was unique among international NGOs at the time, as it was applying a methodology that was about working with local NGOs to identify and respond to their own needs and priorities, and then providing funding and technical support to implement them. According to Sarah, "it was quite an exciting time donor wise because here we were in the UK pretty much the only international organisation specifically focussed on HIV and not all that many others internationally. Donors were really getting going with waking up to that they needed to do something about HIV. The Alliance was a very convenient vehicle that was just sitting there saying give us your funds and we will deliver community action, which nobody else could say at that point!"

It was at this supporters meeting at UNAIDS, that there was an acknowledgement and perhaps a tension that the fund-raising activities of the Alliance were already proving to be more time-consuming than originally anticipated or planned. The tension was that the Alliance was created by a consortium of donors as a mechanism to ensure that donor resources reached community level, but very little of what was asked for and promised was forthcoming. This had an impact on the Alliance's ability to focus on programming and providing the agreed financial and technical support. In addition most of the funding that had been received was restricted, thereby

leaving very little scope for the secretariat to start new programmes or show any form of innovation or flexibility. Only one-third of the funds committed at the first annual supporters meeting in December 1993 had been received by November 1995. In-country efforts at fundraising for linking organisations were not successful either, and the reasons for this were varied as initially this was not part of the Linking Organisations' remit and none of the Linking Organisations had any staff focussing on resource mobilisation.

The Alliance also explicitly at that time, decided not to employ any in-country staff, so this impeded the ability of effective in-country donor relations. However, in the countries where donors were interested in channelling funds through the Linking Organisation, the donors wanted to earmark the funding for specific activities with specific NGOs, which was in direct conflict with the Alliance model. This led to a very frustrated Executive Director saying to the donors that the most important discussion of the Alliance's Third Annual Supporters Meeting must focus on whether or not the Alliance model of financing is realistic and sustainable.

It was already becoming evident that Alliance Linking Organisations (and their programmes) were as notable for their differences as for their similarities. Important lessons were being drawn from the first two years of operation, and some of these lessons were shared with the participants at the supporters meeting:

- NGOs and CBOs should be helped to think of themselves as part of a "nongovernmental sector" with an essential contribution to the national response to HIV and AIDS;
- Programme development is enriched by a process whereby NGOs and CBOs collectively reflect upon, debate and decide appropriate priorities for NGO activities on HIV and AIDS;

- Capacity-building is the Alliance's most important activity, among implementing NGOs and CBOs, and by developing Linking Organisations' skills in NGO funding and the provision of technical support; and
- Effective provision of funds must be combined with the provision of technical support.

The Alliance made the point that NGOs and CBOs have strong links to vulnerable communities and can therefore deliver services in a cost-effective and appropriate manner – this was to become one of the Alliance's mantras and a strong advocacy message for and with donors and other International NGOs.

But already at this meeting, the donors were questioning the role and function of the Alliance. France was concerned that the Alliance was competing with NGOs in their own country for limited development co-operation funding, and questioned the respective roles of the Alliance compared with UNAIDS. The representative from France suggested that the Alliance should consider becoming an implementer for UNAIDS activities. The EU representative however cautioned against too-close ties between the two organisations and the USAID representative indicated that the Alliance's "split personality" – partly multilateral, partly NGO – was exactly why the organisation was attractive to them. The exact delineation of suggested roles between UNAIDS and the Alliance was not discussed, and it was not clear what UNAIDS thought about this proposed arrangement.

The programme plan and budget, which involved expanding activities to 14 countries if the funding was available, elicited a lot of discussion between donors and the trustees. Sarah recalls the sense of immense pressure, "coming from where the Alliance had come from of just a handful of countries, it really felt as if the pressure was on and I do remember discussions with staff and the Trustees as to whether that was the right thing to do?"

But, the Alliance was in a shaky financial position and donors were talking about identifying "emergency funding", "extraordinary additional funding" and a "temporary bridge" to support continued Alliance programming. Unusual terms and phrases to be used for a mechanism that they themselves had initiated and established. Donors however also expressed their concern that the base of donors had not been expanded or diversified and that country-level funding was not more effectively pursued. Some donors, such as the EU, specifically tied any additional funding to the outcomes of the evaluation and an increased donor base.

The discussion at the donor meeting emphasised the widening gap between what the Alliance wanted to do, and what the donors thought the Alliance should be doing.

5.6. Decision time – close down or expand?

Jeff and George were faced with a difficult decision in 1996; a decision that not many people knew was being discussed. Jeff recalls, "I think the question was whether it was a turning point to shut us down. George and I had multiple discussions about whether we felt we should just close it. The evaluation itself and the reaction of some of the donors to the evaluation was such that we seriously talked about just shutting it down."

5.6.1. Alliance evaluation

Was the writing on the wall at the third s supporters meeting in 1995, when meeting participants were reminded by donors that the criteria for the new mechanism was, "that the mechanism should be able to move funds rapidly, flexibly and often in small amounts to a wide variety of different organisations" (Supporters Meeting Report, 1995).

This was not what the model was, and the donors had seen the need for a "mid term" evaluation as originally agreed. They felt that it was necessary to evaluate the effectiveness of the model, particularly looking at how efficient it was in

getting money to community-based organisations. There was however two additional and perhaps fundamental issues that were contentious between the donors and the Alliance, and subsequently with the evaluation team as well. These issues focused on the cost-effectiveness of the model and the impact of the changing donor landscape.

Sarah remembers the evaluation well, "I remember it being mega stressful. It was the first time that we had really been held to account and those early years in the Alliance were pretty amazing. They were exciting times but also slightly anarchic. I think we did really good work but we were also a little bit all over the place. There is nothing like an evaluation to wake you up." The Alliance secretariat and Trustees were consulted and involved in the design of the overall evaluation framework, and the secretariat had the opportunity to express some of its concerns around what the evaluation framework was trying to achieve.

Jeff felt that what the evaluation was looking at was the cost and efficacy of the Alliance in channelling money to frontline organisations, which was clearly a legitimate thing to do. But he felt frustrated that the team did not consider any other aspect of the value chain as a whole. There appeared to have been a lot of tension between the different stakeholders around the Alliance evaluation. Jerker agrees, and recollects of the time, "yeah, I wouldn't use the word tense. Maybe I would, but to the point of hostile, and this is an important difference, because tense can be personality differences. I think it was perceived as hostile by the Alliance staff and the Board – both in the way that the Terms of Reference were drawn up, and in the way that the line of questioning was carried out, and the wilful neglect of incorporating some of our points of view. So there was a sense that we were under attack!"

There was consensus among the donors about the need for the evaluation, but there were differing opinions as to what the evaluation should focus on. The EU was interested in exploring how different NGO support mechanisms allowed donors to work together, but more specifically they wanted to understand to

what degree the expectations that donors had of the Alliance were common and to understand what the Alliance offered donors that could not be accessed through other mechanisms. The Rockerfeller foundation wanted the evaluation to focus on process rather than output or impact, and felt it was important to determine the "value add" of the Alliance, while France felt that some degree of comparison to other mechanisms would be important. The secretariat, and Jeff in particular, felt that the evaluation should place less emphasis on direct comparison with other mechanisms of support to NGOs, but rather explore the Alliance's comparative advantages and disadvantages.

After a number of conversations between the donors and the Alliance, the Terms of Reference and framework were begrudgingly agreed. The specific objectives of the evaluation were identified as:

1. Describe if and how the Alliance has met the expectations the donor group had of It, when it was established and have of it now;
2. Assess the degree to which the Alliance has effectively and efficiently used donor funds to improve co-ordination and planned NGO responses to HIV/AIDS in the developing world;
3. Evaluate the effect that the Alliance's work has or might have on the spread and effects of the epidemic; and
4. Assess if the Alliance is a secure, speedy and accountable agency, which uses donor funds efficiently.

Two consultants, Andy Batkin an economist and project manager and Peter Gordon a consultant in sexual health, were contracted to carry out the evaluation. The outcomes of the evaluation would provide the donors with information to guide their decisions regarding the future funding support to the organisation. The evaluation involved two country visits to Senegal and the Philippines, interviews with Trustees, secretariat staff and other stakeholders, including donor and partner agencies. The evaluation also spent considerable time reviewing source documentation.

There was concern from some respondents that the evaluation was premature. The Alliance at the time of the evaluation had been in existence for 30 months and some felt that it took longer than 30 months to prove oneself. The evaluators felt differently. Jeff also had another concern about the timing, "when it came out, there was very little HIV money around, UNAIDS was absorbing a lot of the HIV money that did exist, the original sort of sense of ownership by the donors had gone really. Already by the end of 96 we were clearly another NGO. We were a rather unusual NGO, but we were just another NGO, and so an evaluation that raised serious doubts about our business model was inevitably a turning point."

The external evaluation came up with 24 recommendations and had two strong fundamental messages, which the Alliance used to its advantage. The messages focussed on the fact that the Alliance was delivering on the expectations of the donors and the report strongly recommended that donors continue to support the Alliance – albeit it with a few modifications (Evaluation Report, p 17).

The report from the consultants went to a great deal of effort to explain the recommendations and criticisms, "The mission firmly and without reservation recommends that donor support to the Alliance continue. The evidence set out in the rest of this report is that the Alliance is delivering on the original expectations of donors. The Alliance is succeeding in stimulating an impressive NGO response to the epidemic and the LO methodology, was well chosen. The criticism and recommendations made in this report are designed to improve the strength and cost-effectiveness of this new mechanism of donor funding. It clearly works well already, and in time it may come to be a model for donors seeking to work with NGOs in other sectors. Provided that the recommendations made in this report are generally accepted, we believe that the Alliance is now in a position to manage a substantially larger volume of donor funds. The points of criticism are bluntly stated, but the mission's overall evaluation is positive. (External evaluation report pp 26 – 27).

The Alliance Trustees and secretariat however disagreed with three of the recommendations: 1. the Alliance's secretariat becoming the donors' secretariat, 2. the focus of technical support only be on HIV issues, and 3. the overall mission of the Alliance.

There was a sense that if the Alliances' secretariat became the donors' secretariat this would be confusing and inappropriate particularly as it relates to the roles and function of the Executive Director and Trustees. Only focusing technical support on HIV issues was seen as inappropriate and unrealistic, as additional technical assistance was often required in a variety of other areas including methodological issues, management, organisational development and accountability. The secretariat therefore felt it ineffective to only focus technical assistance on HIV issues, and the mission was broader than just providing a mechanism for funding.

5.6.2. Where was the disconnect?

Jerker felt that there was a disconnect between donor words and their actions, which according to him was not unusual in development or politics, "you come up with strategies and grand plans, but are you going to put money behind it? It does not necessarily follow, and if the organisation is not performing on the benchmarks that you set for the grand vision with lots of funding, then you can criticise the organisation and justify withdrawing funding".

The evaluation picked up on these differing perspectives, as three of the founding donors were generally quite content with the achievements of the Alliance. The other three however were concerned about the following issues which are highlighted directly in the evaluation report;

- A sense that the Alliance was losing its roots as a donor-inspired agency for transfer of funds and technical assistance (TA), and was increasingly coming to resemble an autonomous international NGO in its relations with donors

- Inadequate attention to donor policies and priorities
- Inadequate responses to comment and concerns over field activities
- Inappropriate communication with donors
- Insufficient provision of information on field-level outputs and impact
- Insufficient attention to mobilising resources from other donors and from country programme budgets.

These concerns confirmed that, for some of the donors, the model was changing. This resulted in some of the donors feeling distanced from the model and mechanism that they thought they had created. The donors felt that the Alliance was no longer "donor-controlled", and that the Alliance was increasingly going its own way with insufficient sensitivity to policy and financial development among its funders. (Evaluation report, 1996). But Sarah indicated that she found the donors' ownership of the Alliance challenging, "you have your donors and of course they have some ownership over specific projects but you have a sense of very much being an independent organisation. In the very early days of the Alliance, I felt quite owned by the donors."

The distancing was not intentional. The Alliance was not in an independence struggle and certainly did not want to be seen as an ordinary NGO, but did feel that the perceived financial security and donor contributions would be more forthcoming thereby offering it a more certain basis for planning and expansion. The donors, as alluded to in comments by Jerker, had their own reasons for questioning the changing relationship, "with the evaluation came a crisis in funding, a crisis of confidence shall we say from the EU in particular. The Brits and the French too, but for different reasons as I think the French had their own reasons for disengaging, and frankly they were political and had to do with the response in France.

So there were slightly different reasons. SIDA kind of didn't really ask too many questions, and they're a kind of loyal supporter in general and they'll tend to

stick with it." Sarah feels that the evaluation fundamentally changed the process around funding for the Alliance, "it is almost like we had not really needed to do fundraising up until then. It had been a presumption that the donors would pay so it fundamentally changed that. It felt we were into the real world of proposals and fighting for the money."

The donors felt that coordination and communication with them had been ad-hoc as no one within the Alliance had responsibility of communicating with donors. This function was undertaken by IFH during the establishment of the Alliance. The fact that the donors felt that the organisation was starting to resemble an autonomous international NGO and felt 'distanced' was a little perplexing, especially since the donors supported the creation of the Board of Trustees and approved the need for the structure to be legally registered as an organisation/charity.

The evaluators listed four possible solutions to the "distancing problem", and these focused on:

1. **Reconstitution of the Board**: there was a suggestion that donors or donor nominees also serve on the Board. There was however an inherent conflict of interest with this solution as the evaluators felt that the present Board members would become distinctly second-class citizens, and the important role that they had played to date would be diminished.

2. The evaluators however felt that there was no sense that the Board was trying to push the organisation into a new direction, nor was it ever likely to play this role – which one assumes is the role and function of a Board. They stated that the Board had not been a key determinant of policy as the agenda for Board meetings was determined by the secretariat – again, another core function of a Board.

3. **A new secretariat unit**: this suggestion was closely linked to options iii and iv below, but many respondents spoke of the need to establish a unit within the secretariat to support communication with donors. The evaluators did not support this option if it included the hiring of additional staff, but they were happy to support it if it implied options to strengthen the Executive Directors' liaison with donors.
4. **Improved consultation**: some donors had already felt as if they had lost control of the organisation, so suggestions to increase consultation and communication between the donors and the secretariat would not necessarily increase the donors' sense of ownership.
5. **A donor secretariat**: the evaluators proposed that the role and function of the Executive Director's job description be changed to make the role more one of a secretary to the donor group, and by implication making the Alliance secretariat to the donors (and the Board).

5.6.3. An important decision had to be made

It was a difficult time for the leadership of the organisation, "we felt besieged and we felt unfairly treated and misunderstood for all those value added things," exclaimed Jeff. He and the Board chair were having a number of discussions about the implications of the evaluation, "And a lot of those were bilateral conversations before we went to the board, because together we felt that we had to agree as chair and executive director on how we wanted to react to this thing, and then we had to try to get others on board."

Jerker feels as if the Alliance was caught in a trap, "it was a very nervous time and we panicked, or no that is too strong a word. Jeff was possibly panicking slightly, not panicking in the sense of losing control, but panicking in the sense of we're really at risk here, and we were!" According to Jerker, the Board's chair was more pragmatic about it, "George's line on this was, 'well you have two

options. Either you grow or you fade out of existence. You pack up and go home!' I liked the way that George put things, well his advice at least was in a straight and no-nonsense manner," quipped Jerker.

Jeff's frustration at the evaluation teams' inability to consider others aspects of the value chain is still quite evident, "so catalysing a community response, setting up a national linking organisation that would be an advocate and a champion, doing technical support, quality assurance type work, extracting lessons and sharing them, none of that was seen as value. All of that was seen as a delivery cost to the goal, which was money at the frontline and by that criteria the evaluation concluded that we were doing a pretty lousy job!" exclaimed Jeff. He does acknowledge too that they may have moved on some arguments, "it may have been that we succeeded through a bunch of arguments with the evaluators at getting them to acknowledge, at least to some degree, the value of these other functions. But certainly the evaluators were at best sceptical and largely dismissive of anything having value except for money at the back end, the front end!"

The evaluation was a turning point for the Alliance. According to Jerker it was a turning point because the honeymoon was over, "what we had been promised was being taken away from us with this device of evaluation, which felt very manipulated and a sense of betrayal in terms of some of the donors. Some donors stayed with us and others did not." The Alliance also learnt from the process, as Jerker again reflected, "politics of course is organised hypocrisy, in the sense that you make promises and plans and that is how you move forward. But then you have delaying tactics or deflecting tactics and you do not necessarily do what you say you are going to do. But we did learn. We often used the simile of its kind of like adolescence, coming of age, growing up and learning reality and actually the world isn't as good as we thought. So, I think it was definitely a turning point and it did push us into the period where we were forced to become a lot more creative, possibly more contesting within, but it was a good period as we went through trial and tribulations as a group".

6. The scale-up phase (1997 – 2000)

"It was a big struggle with some LOs, just because people had so many day-to-day pressures and demands and even if people were willing to do policy, it often got de-prioritised"
Sarah (Middleton) Lee

This phase of the Alliance's history focused on scale-up and impact, including building on and strengthening initiatives that had already happened. The Alliance was established – either through Linking Organisations or programme activities – in 12 countries (Bangladesh, Brazil, Burkina Faso, Cambodia, Ecuador, India, Mexico, Morocco, Philippines, Senegal, Sri Lanka and Zambia). George spoke about finding new ways of expanding impact, as well as expanding the Alliance's area of work into operations research and contributing to global learning about HIV through policy. The Alliance expanded its scope of work from primarily low prevalence settings to a combination of low and high prevalence scenarios in order to strengthen and broaden long-standing programmes.

6.1. Scale-up and impact

Donors endorsed the scale-up strategy in February 1997, including a number of key features that were strengthened in the new strategy. These included changes in the way that the Alliance did business, as there was a greater emphasis on the Alliance's technical role and contribution to supporting and strengthening community-based responses. This meant that the Alliance focused on existing initiatives that could be strengthened and influenced rather than supporting new programmes.

The Alliance made a commitment to experimenting with new methodologies, described as development and testing of tools, operations research and advocacy linked to policy. The Alliance felt that its added value was to influence practice indirectly rather than directly. There was a fundamental shift from the donors, as to who and what the Alliance was. It was no longer the global mechanism to 'simply' deliver funding to community level, but there was a growing appreciation and recognition of the Alliance's expertise and value add with

regards to improving and strengthening community responses to HIV. As Jeff stated, “our value add was this to be in learning, influencing and leveraging rather than funding.”

There were a number of key developments that shaped and defined the Alliance during these years. While there was recognition from the donors that the Alliance had come into its own, the Alliance secretariat adopted a very different approach to developing the new strategy. The Alliance had to start focusing on sustainability of the linking organisations and address the donors’ need for reach and numbers during the scale-up phase.

6.2. A new strategy focusing on reach

According to Jeff the new strategy was developed as a result of the external evaluation process and ongoing consultations with the Alliance donors. The new strategy was also however developed in a very “non Alliance” manner. There was no consultation (formal or informal) with partners in developing countries, and linking organisations were informed (rather than consulted) of the Alliance’s new goals and strategies. Some of the linking organisations were also required to adjust their own approaches to meet the new monitoring and evaluation requirements. Importantly very few of the Alliance’s linking organisations contributed to this shift in strategy and according to Jeff very few fully understood it.

Jeff refers to this tension, “one of the fundamental tensions was between buying into the delivery of results defined by a donor, and virtually all the institutional donors out there, even the private ones had their own results frameworks, and very few donors were looking to fund good ideas. They were looking to contract actors to deliver on their own results framework. There is a massive tension between that and a vision of the Alliance as something that was set up to support community responses”.

Although Jeff was initially frustrated and angered by this tension, he soon realised that it was within this tension that the Alliance's strength lay, "there were organisations that did a better job of delivering on what donors wanted, and a classic example is Family Health International (FHI). The fact that they did a better job was reflected in how much money USAID put into them, because USAID could get exactly what they wanted to buy from FHI. FHI did a lot of very, very important work and a lot of it much more solid technically than the Alliance's work, but if you evaluate FHI's impact, I think, in many places in a defined period of time compared to the Alliance's, I think the FHI would often do better and look better. But, I think if you look at what is there after a few years of the project, I think that the Alliance looks better", said Jeff.

6.2.1. Showing results

Barely a year into the new strategy one of the Alliance's biggest donors introduced new funding requirements related to measuring the number of people reached by Alliance programmes. This was in 1998, and Jeff felt that this new requirement was at odds with the goals of the new strategy as it introduced conceptual difficulties to performance measurement and ownership. Jerker, who by now had become the Director of Field Programmes, admits that the Alliance was initially challenged by showing reach, "recognising the difficulty of actually tracking the reach, and obviously the different kinds of reach you can have, the different kinds of activities and messages and so on, and the tyranny of the numbers in terms of having to reach high numbers, and that dulling down in the focus of what you are actually trying to do".

According to him two things came out of this process for the Alliance, "on the programmatic side I saw that very much as a game we had to play with donors, and we came up with kind of simplified spread sheets and how you can guestimate on the basis of some monitoring that you're doing, so how you can guestimate and generate numbers. That was playing a game in a sense. So for example, distribution of leaflets and how do you know what kind of reach you might have, which is a kind of nonsensical question, but I guess somebody wants

their number. The reporting system was well intentioned in trying to set up a system for monitoring data, which spread to every partner at field level, but actually it did not say much or that data was not necessarily very meaningful and quite artificial, and that becomes very cumbersome when it became very kind of institutionalised."

The other aspect of the numbers discussion was focusing on prevention work and linking this to care work as the Alliance was interested in seeing whether key populations were getting effective support. It was for them about seeing whether there was impact in terms of good combination services and support to make a difference in the lives of the key populations.

Responsibility for showing numbers also led to the Alliance differentiating between a Linking Organisation Programme and a non – Linking Organisation Programme.

LO Programmes had to report against the following:	**Non LO Programme could use the most relevant indicators from the following:**
Number of people from vulnerable populations reached with supported NGO/CBO programmes and services	To build partner NGO institutional capacity to meet demands for technical support from local NGOs/CBOs
Number of supported NGOs/CBOs that meet a minimum of three out of four of the following criteria: - Conducted a formal population assessment before implementing current intervention. - Reach a focused and vulnerable population rather than 'general public' - Conduct more than just	To develop partner NGO staff capacity to serve as technical support providers to local NGOs and CBOs

awareness raising activities in programmes - Raise supplementary resources outside (LO name) and/or work in partnership with public or private sectors.	
	To build partner NGO institutional capacity to identify and undertake strategic partnerships
	To support partners to identify, document and share lessons.

It was also the first time, that a formal criteria around the selection of Linking Organisations was established. These criteria included:

- A Linking Organisation is an indigenous organisation;
- A Linking Organisation provides support to other NGOs or CBOs in their country (either financial or technical support);
- A Linking Organisation has an ongoing relationship with the Alliance, including some degree of financial support and/or technical co-operation;
- A Linking Organisation agrees to share information with the Alliance secretariat on a regular basis against agreed indicators; and
- There is mutual agreement and desire by both the secretariat and the partner that the partner is referred to as a Linking Organisation.

It was decided that the organisations in Zambia and India could not be considered to be Linking Organisations as they were not indigenous organisations.

6.3. A stronger policy focus

The secretariat focused and strengthened its international programme on four "action areas" (i) Alliance External Relations, (ii) Linking Organisations External Relations, (iii) promoting policy and practice and (iv) monitoring and review. While there was a greater focus on public policy and advocacy the Trustees insisted that any programmes that focused on policy and advocacy had to provide support to LOs in these areas.

Sarah, who was initially appointed as the policy officer, spoke about the need to manage some of the tensions between Linking Organisations needing to understand and own policy and advocacy work and the need for the secretariat to advance policy and advocacy work. "It was a big struggle with some LOs, just because people had so many day-to-day pressures and demands and even if people were willing to do policy, it often got de-prioritised". There was also a gap in terms of documenting and capturing the policy work that was being done. Whilst good work was being done, very little was being written up, and there were tensions within the secretariat as some staff felt that the secretariat should only focus on programming and not do policy work at all. "They just thought programme work is the proper work and they did not see what policy work would bring, what difference it would make, how it would benefit communities on the ground" said Sarah. She felt that policy work did seem very distant and irrelevant to people on the ground and in the secretariat, "some people just did not get it, which was quite hard and I found that very hard because I sometimes felt my whole area of work was being questioned and under-valued."

Jeff was focusing a lot on high-level global policy and advocacy work, "he was doing most of the Geneva, Brussels, Washington and the UN type work. A lot of the policy work that I was doing was probably policy with a small p rather than a big P. I was looking at things like the participatory approaches that Jerker and colleagues were developing. I was working on trying to document and share good practice" remembers Sarah.

6.4. Care and support

Although there was an explicit need defined to focus on care and support activities when the Alliance was set up, the programme for this area of work only became clearer in 1997 and 1998. This was probably as a result of the announcement of antiretroviral (ARV) treatment at the 1996 International AIDS Conference in Vancouver. (IAS, 1996). Up until this time, the Alliance's focus on treatment and care was primarily around psychosocial support issues.

In September 1998 the Alliance held a two-day retreat to discuss care and support related issues with the specific aims being:

- To discuss issues related to the Alliance's involvement in care and support activities
- To define and agree principals, parametres, constraints and priorities for the Alliances involvement in care and support activities;
- To identify gaps in the current approach to working with country programmes in order to support the development of their work in care and support; and
- To identify the next steps in the Alliance's approach to care and support activities.

The retreat focused on finding the right balance between curative and palliative care, which according to the report from the retreat was described as "a concept that is new in many of the communities where we are working" (Care and Support Update, October 1998). The retreat agreed to develop an Alliance "bottom line" that would guide LO strategic thinking and planning on care and support. There were a number of suggested bottom line criteria that was put forward to the Trustees for their approval. These were in some ways contradictory but highlighted the struggle that the Alliance was facing.

These included:

- Alliance funds could not be used to pay for ARVs. The only exception to this was to purchase AZT for the interruption of maternal-child transmission. The proposed policy stated "While the Alliance discourages LOs from using funds for the purchase of AZT, we believe that this decision should be made locally (Care and Support Update, October 1998);
- Alliance funds cannot be used to pay for drugs that are not approved by the national governments;
- Funds from the Alliance should never be used to pay for drugs alone;
- Staff of the Alliance and Alliance LOs should not distribute drugs or supplies directly;
- Drugs and supplies purchased with Alliance funds should be destined for the poorest and most marginalised within the communities being served; and
- Drugs and supplies purchased with Alliance funds should only be used with HIV- and STI-related projects.

6.5. Expansion – an Africa AIDS Alliance?

By 1999 the Alliance had made a limited contribution to the response to HIV in Africa. This was related to a number of factors including resources, relevance and whether the Alliance was welcome or not. Donors were shifting their attention and resources to what many perceived to be growing HIV epidemics in Asia, so up until 1998 the Alliance was only able to invest 11% of its total resources in Africa (versus 43% for Asia). The Alliance, which at this time only had a presence in Zambia, was struggling to attract additional resources, as donors were more inclined to support those international NGOs with established reputations and experience in sub-Saharan Africa. Many countries in sub-Saharan Africa had already developed relatively strong civil society responses and many questioned the need for additional presence that would provide technical support, and possibly compete with indigenous NGOs for funding.

The Alliance conducted formal needs assessment with NGOs in seven African countries and had developed programming and implementation experience in several others. There was recognition from partners who were interviewed that there was a need for capacity-building and focused technical support, and ideally capacity-building expertise from Africa. UNAIDS had developed what the referred to as the "international partnership".

A proposal that was discussed with the Trustees was therefore around creating an African AIDS Alliance. It was not to be a regional office of the Alliance secretariat, but an affiliated office that would over time develop and take over full execution responsibilities. The potential functions of the "Africa AIDS Alliance" would include:

- Supporting existing Linking Organisations in Burkina Faso, Senegal and Morocco, and the country programme in Zambia;
- Managing the development of alternate community mobilisation and capacity-building projects at country levels;
- Seeking funds and starting up new Linking Organisations where such a model of national-level support would be appropriate;
- Promoting and participating in appropriate in-country learning and training activities;
- Providing a wide range of related technical support services to governments, donors and multilateral agencies;
- Channeling regional funds to country and community level;
- Ensuring the flow of information and expertise bottom-up, top-down and horizontally.

The rationale was that since the organisation was to be based in Africa in would be able to influence African policy makers, be more attractive to donors and be more likely to establish a role as a regional leader. The idea was discussed with the UNAIDS Executive Director, Peter Piot, as it was considered essential that he

and UNAIDS supported and endorsed the idea of this new regional organisation. In addition to the personal and organisational support of Piot and UNAIDS, the Alliance estimated that funding of between US$ 1.5 million to US$ 2 million per year would have to be secured and appropriate consultation with African civil society must take place, prior to moving forward.

According to Jerker the Alliance was also looking at what the epidemic in Asia was doing, “we need to understand that type of response would be needed in different places. At the time care was not very much on the agenda and the focus was still pretty much on HIV prevention”. The set up a regional programme that focused on a number of technical strands around key populations, “there was actually doing something sensible about sex work or with sex workers, and drug use too. We also worked with MSM, because at the time there was not much interesting or progressive work on MSM, or sexual rights for that matter,” said Jerker.

By late 1999, the secretariat had decided not to pursue the idea of an African AIDS Alliance, but rather to focus on developing key strategic partnerships with existing regional programmes, the development of specific regional activities from the Zambia base (which had now become a country office) and the possibility that Linking Organisations could take on a more regional function.

6.6. Sustainability – myth or reality?

An ongoing challenge for the Alliance during its first ten years, and a struggle that has certainly continued until today, is the sustainability of a Linking Organisation and the fine balance between quantity (expanding into many countries) and quality (strengthen programmes in existing countries). Jerker feels that some of these challenges are built into the model by design, “but I think they have become exacerbated to the extent that the Alliance is more of a BINGO [Big International NGO], and to the extent there is the tension between what the Alliance does and costs, and what is done and what it costs at LO level”.

But, according to Jerker, the Linking Organisation is a risky business, “it is not a guaranteed success. They can succeed and sometimes they do not. It is easy to over-invest and go on for far too long, but other times it works incredibly easily, and although you may not have much money for it, it just works anyway for some reason. The sustainability of a Linking Organisation is country-by-country, and they certainly can be sustainable, but this depends very much on what resources are available”, alluding to the fact that many of the LOs in Africa were dependent (and still remain dependent) on AID money for their continued existence.

Jeff, in his report to the Trustees Meeting in 1999 spoke of the re-medicalisation of HIV policy discussions, and highlighted a number of additional sustainability issues that the organisation was confronting.

There was a realisation and increasing evidence that most income-generation activities were not as effective as many initially thought. The reasons were varied and related to ineffective implementation, unclear objectives and lack of sustainability strategies. However, a number of LOs were using income-generation activities as part of their intervention packages and seeking funds for the implementation of these activities.

7. Conclusion

The world of HIV was changing towards the end of the millennium. Exciting and dramatic results from the HIVNET 012 trial in Uganda (1999) demonstrated a dramatic reduction in vertical transmission of HIV through the use of a single dose of Nevirapine to mothers living with HIV (Guay et al, 1999). There was ongoing and increasing pressure to increase antiretroviral access in the South (Reich and Bery, 2005). There too was growing concern that the pharmaceutical industry investment in new HIV therapies would flatten as there was increased pressure for "low-cost" access in the south. The donor landscape was beginning to change and donor funding was being diverted from behaviour change to more medicalised approaches such as new prevention technologies and investment in STD programmes rather than the community mobilisation, behaviour change and human rights (O'Malley 1998).

The Alliance too had changed – it had to. There was a well-meaning and earnest attempt from donors wanting to get funding to community groups to support them in defining and shaping their own local responses. But, were they perhaps too simplistic and naïve in thinking that the mechanism could 'simply' be a conduit for financial resources? It is also difficult to imagine what the Alliance would have been had the organisation formed first and then approached donors for funding, but perhaps that is not so important now. There are probably many "what ifs" or "if only's" that could and would probably have taken the organisation into a very different direction, but the model by and large worked – local ownership and involvement of those most affected.

Although there were two differing visions for what the Alliance was, they complemented each other and came from a place of wanting to make a difference. The leadership was visionary and determined, and pushed the boundaries of community participation and involvement. It may have been a completely different organisation had either of the two other potential Executive Directors taken the reins, but through the strong activist, personal drive and

commitment from Jeff and eventually most of his team, the organisation became what it is today. An organisation which remains focussed on supporting community action on HIV.

It was a time in the epidemic where there was very little hope; HIV was destroying communities, there was very little if any sign of effective HIV treatment and HIV technical capacity and skill was weak. So it is understandable that the reaction was to try and get resources to groups on the frontline, to enable community groups to define, shape and implement programmes that work for them. It is unclear how much discussion happened between the donors in the run up to the first supporters meeting – but it is clear that by the second supporters meeting there were differing opinions and views, among the donors, of what the Alliance model should be.

The Alliance was founded to respond to a specific need and has largely been shaped and defined by the personalities involved in the Alliance family. The Alliance has also shaped and defined many who have worked for the organisation, "many of the Alliance family end up in other institutions, and the reality is that if you look around the developing country people who are making the biggest difference on AIDS in their countries, a remarkably large number of them, including people working now working for the very technical organisations and the UN, got into this work through some affiliation with the AIDS Alliance and learned their skills", said Jeff.

There is no doubt that one of the successes of the Alliance is its ability not only to learn from Linking Organisations and organisations working at the community level, but its ability to integrate and adapt the learning and allowing that to shape what the organisation was to do.

The organisation advanced the concept of community participation and involvement and helped define participatory methods for working on HIV with communities, especially those most marginalised. It demonstrated the impact

that community-based HIV prevention and care programming could have linked local advocacy to global policy and vice versa. The Alliance helped shape and inform a number of global policy initiatives, such as the Greater Involvement of People Living with HIV/AIDS (GIPA) and was one of the first organisations which integrated this principle into its model and advocated for others to do the same.

The Alliance is commemorating its twentieth Anniversary in February 2014. The organisation is a very different one from 20 years ago, but the principles of supporting and enabling effective community- based responses are still very much engrained in what the Alliance does. The baby is on the verge of becoming an adult and has undoubtedly had its own set of challenges related to puberty and growing up. The organisation continues to deal with ongoing challenges around donor resources, sustainability of Linking Organisations, the role of the secretariat and the changing HIV environment, and in dealing with those challenges lies the organisation's strength, as it needs to constantly adapt and define what it is doing to remain relevant.

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