

Rhode Island Project/AIDS:
The Birth of a Community Organization

David A. Eligator
Brown University
December 1987

It is hard to determine when Rhode Island Project/AIDS actually began. While the official date of the organization's incorporation was September 16, 1985, the Project existed long before then as an informal group. This group, which was composed of concerned people in Rhode Island's medical and gay communities, came together to deal with the growing problem of AIDS, an issue they felt had been ignored by the government on both national and local levels everywhere. The goals of this group were threefold: AIDS education to the general public, intervention with those at high-risk, and direct support to those with AIDS or ARC and their families. Today, over two years after incorporation, Rhode Island Project/AIDS is a well-established organization. While the Project was run from a post office box and someone's living room only eighteen months ago, the organization now occupies a four-room office in a centrally-located State office building. And as of mid-November, 1987, the Project had already assigned over seventy buddies to provide direct support to persons with AIDS or ARC, produced various educational pamphlets, sent trained volunteers to present AIDS information to hundreds of schools, community groups and professional groups, and the organization continues to increase and expand its services. In this paper I will examine several the historic development of Rhode Island Project/AIDS. I will do this by breaking the Project's history into three periods. I have titled these periods "A Problem Arises", "A Group Responds", and "The Project Incorporates". I will then examine the reasons behind the Project's success in responding to the AIDS crisis in Rhode Island.

A Problem Arises

Before 1983, Acquired Immune Deficiency Syndrome was not a problem in Rhode Island. No cases at all had been reported in the State, despite proximity to

Boston and New York, which both had a large number of AIDS cases. Few people in Rhode Island were concerned, since AIDS was not felt to be a particularly large concern by local and national governments, even in those areas with many AIDS cases. In fact, many Rhode Islanders still did not even know what AIDS was.

In 1983, this situation began to change. By June there were three confirmed cases of AIDS in Rhode Island.¹ By September, one of these patients had died and there was another case suspected.² By October, a second person had died of AIDS.³

Soon after the state's first AIDS death, the Rhode Island Department of Health began receiving increasing numbers of AIDS-related calls from anxious citizens.⁴ At this early date, most of the state's health professionals knew very little about the disease themselves, and were therefore little able to educate others. Moreover, the fact that AIDS was so commonly associated with intravenous drug abuse and homosexuality created a situation in which many people felt embarrassed or incriminated by simply discussing AIDS. This atmosphere was strong in Rhode Island where, because of a small-town atmosphere and a rather conservative, mainly Roman Catholic population, homosexuality is relatively hidden from view and not acknowledged publicly. Because of factors such as these, the need for AIDS education for professionals and for the public was becoming greater each day in Rhode Island. There needed to be a visible and accessible source of accurate AIDS information, especially since there was already such mystery and myth surrounding the disease.

While the needs for education increased, so did the needs of the state's early AIDS patients. One of the major needs of these persons with AIDS (PWA's) was in getting SSI Disability benefits. Medical care for AIDS can be tremendously expensive, and in the late stages of the disease, AIDS patients become too ill to work.

Getting onto assistance is frequently a lengthy and complicated process. Early AIDS patients in Rhode Island found the red tape involved to be tremendously discouraging. This was understandable, especially since these people were very ill and had brief life expectancies. Marjorie Stenberg, a Nurse-Epidemiologist at the Veteran's Administration Hospital in Providence, was well aware of her patients' problems obtaining disability benefits. She relates that in 1983,

One of our patients got his first Social Security check seven months after the application had been made. It arrived on the day he died. Our second patient...took over nine months to get the Social Security, and it arrived the week he died."⁵

Getting welfare benefits was another problem. One of Stenberg's patients was in such financial distress that he used to sleep until noon so he could skip a meal and leave more food for his children.

Another problem for PWA's lay in health care and other services outside the hospital setting. As the number of cases grew in Rhode Island, the need for comprehensive care became obvious. When AIDS first surfaced in the State, organizations such as the Rhode Island Visiting Nurse Association and Hospice Care of Rhode Island were still uneducated about the disease and were therefore unable to provide home health care or hospice services to AIDS patients. No nursing homes in Rhode Island would accept an AIDS patient. Even a task as simple as finding a dentist or a barber was sometimes a problem for a person with AIDS. This lack of services continued even after a patient's death: no funeral homes would perform embalming or burial services for deaths related to AIDS.

A third problem, perhaps the most important of all for Rhode Island's first AIDS patients, was the overwhelming need for friendship and compassion. The reality of death around the corner naturally created great emotional needs for those

stricken with AIDS. Persons with AIDS in Rhode Island (as elsewhere) became modern-day lepers, shunned by a frightened and hostile public. Not infrequently, the "taboo" issues of homosexuality and intravenous drug abuse led to rejection by one's own family and friends. The possibility of a lonely death was quite real for a person with AIDS at this early time.

While the problems of the patients themselves were important and many, a second dimension of the AIDS crisis soon arose: addressing the emotional needs of the patient's family and loved ones. A family member with AIDS creates great stress among the rest of the PWA's family. In the early years of the crisis in Rhode Island, AIDS families had few other emotional resources than those health care providers treating the ill family member. Stenberg notes,

"Towards the end of any AIDS patients sickness, what you are nursing is the family, not the patient anymore. There was nobody to answer their questions, there was nobody to reassure them."⁶

If the ill person was gay or an IV drug user, the family stress was sometimes especially difficult. Caregivers discovered that AIDS often created a unique stress and upset in families because of rejection and isolation from less understanding or compassionate others. An article in the Providence Sunday Journal from December, 1983, described this problem:

AIDS is a disease that does more than kill. It shames....Not only must family members cope with the shock of watching a loved one die from the disease, they must also endure the suspicions of others who would rather pass judgement on a lifestyle than show empathy for human suffering. Mrs. Manfredi remembers one day around the end of July. She was in the hospital gift shop, waiting to visit her son three floors above. A woman working there happened to be talking about AIDS, saying how she had read all about it in *Time* magazine. 'The faggots,'

the woman said. 'They deserve what they get.'⁷

It soon became clear that a public response was needed for the state's AIDS-related problems. There needed to be an educational campaign aimed at the gay community, at intravenous drug users, and at the rest of the public as well. There was also a need for specially-trained AIDS case workers, who could take care of obtaining benefits and services for PWA's and provide emotional support for both patient and family.

Since AIDS was quickly becoming a public concern in Rhode Island, a response should ideally have come from the State government. But the government did not respond to AIDS. This was because it was unable to respond, and for three reasons. First, it was highly unlikely that the State could reach either of the two groups primarily at risk, intravenous drug users or gay men. This is because both of these groups are relatively hidden from public view and hard to identify. Additionally, both groups are considered criminals by Rhode Island State laws; gays have a strict sodomy law to contend with, while IV drug users can be arrested for simply possessing a hyperdermic needle. It is natural that gays and IV drug users would mistrust virtually any interaction with the government for fear that these laws would be enforced. Bob Hitt, one of the cofounders of Rhode Island Project/AIDS, comments, "It's difficult to have a State agency that [gays or intravenous drug users] could feel comfortable walking into without looking for the hidden cameras".⁸ Another founder agreed,

When State government has a drug enforcement agency as part of its function, it has a very enforcement mentality. You can't expect those people to be concurring very often with those of us saying 'never share your works'. They're saying 'don't get high'. We'd say that, too, but I think we take a more realistic, pragmatic approach to the prevention of transmission than an enforcement agency would.⁹

Second, because of the contraversial political and moral aspects of AIDS, any government- sponsored educational campaign or, indeed any other expenditure dealing with AIDS, would likely be criticized and opposed by the state's strong Catholic lobby and by other conservative groups. Conservative citizens didn't want their tax dollars to go to homosexuals and drug users. The Catholic church didn't want tax dollars to be used to instruct people on the use of condoms. And in the Rhode Island State House, most people were conservative and Catholic. Third and finally, dealing directly with the problem of AIDS required compassion and dedication, which necessitated this work to be undertaken in the private sphere as opposed to the public sphere. Government is not in the business of caring. To government, people are statistics and groups of people are just that: groups. Tom Martin, a Black lawyer who was involved in the early grant writing for Rhode Island Project/AIDS, believed that

...the government felt that, at least the personal aspect of AIDS, what the Project was doing, should be left to a private concern. The sense of compassion, the sense of understanding and so forth, they just did not have the personnel to deal with that.¹⁰

While it was clear to those dealing with AIDS that a public response was needed, it was also becoming clear that this response was not going to come from the government. Understandably, the lack of government response angered many gays, for it added to a feeling that government cared little about them as a group or as individuals. Bob Hitt commented,

You're talking about two primary areas of the population that are considered by mainstream America to be dispensible, namely intravenous drug users and homosexual, bisexual men. The response from government on every level, until today, has been negligible

considering the extent of the problem. When you look at Legionnaire's Disease and the twenty-nine deaths that occurred...and the amount of money that was pumped into Legionnaire's Disease within the first week of diagnosis as compared to the thousands of deaths from AIDS over the course of the last seven or eight years, you can see that the political response is really inadequate...It is homophobia and the inability to deal with the drug addiction problem.¹¹

Indeed, a quick look at the history of the Gay Rights movement shows that our government has been either indifferent or hostile towards gay men and lesbians. This led some people to view the government's inactivity as a passive genocide of gays. While this view may seem a bit extreme, there were certainly enough instances of governmental homophobia to support it. For example, while opposing a proposal to allow the vending of condoms in Traverse City, Michigan, City Commissioner John Markl asserted "...that homosexuals were the cause of AIDS and that 'a quick cut of the scapel' on homosexuals would prevent its spread."¹² On the Federal level, President Reagan signed into law a new immigration bill in 1986 that barred gay people from entering the United States.¹³ Reagan also did not even mention the word "AIDS" until 1987, the same year that AIDS deaths in the United States hit the 20,000 mark.¹⁴

Negative public sentiment toward I.V. drug users was another contributing factor in the lack of governmental response. While Rhode Islanders had little understanding or sympathy for those who used intravenous drugs, over half of State's AIDS cases during the first two years were contracted through intravenous drug use. This percentage was significantly higher than elsewhere in the nation, making Rhode Island the second highest State in percentage intravenous AIDS cases next to New Jersey.¹⁵ High incidence of intravenous drug users led to ambivalence about AIDS from the majority of the public.

While Rhode Island's gay community was becoming concerned, so were

many people in the local medical community. Linda Durand, a Nurse-Practitioner at Rhode Island Hospital agreed that the government seemed to lack caring and commitment to the problems posed by AIDS.

The government has historically not responded to this problem very well....The populations are the underdogs--the gay population, the IV drug use population. People really don't care about these groups....It's not a money-making proposition to deal with HIV problems.¹⁶

Another health care worker felt that someone needed to pry the government into action. "AIDS just wasn't a priority; they felt it to be a gay disease".¹⁷ Time went by without a response to AIDS needs, and those treating AIDS patients were under greater and more varied demands. The unwillingness or the inability of the government to respond to AIDS created the need for a community response.

A Group Responds

One of the early leaders to address AIDS in Rhode Island's gay community was Bill Pellicio. Pellicio lived in Providence and specialized in counseling gay men. A gay man himself, Bill kept himself involved in national gay issues. In 1982, Bill and his friend Pete, who was a physician, went to the National Gay Health Conference in Denver. It was there that they both became informed about AIDS. When Bill returned to Rhode Island, he began to share his concerns with others in the gay community:

Before AIDS was much of a reality in Rhode Island at all, I was already experienced to what was happening on a national level. I had already begun to meet people diagnosed with AIDS in New York. So I came back here knowing that it was something we'd all be doing very soon, and particularly myself - I was working with so many gay men and needing to

really alert people to what was happening.¹⁸

After the Gay Health Conference, Bill realized that without government response, AIDS needs would not be met. So, in order to "fill the gap", Bill and Pete began to work informally with patients and their families, hoping to offer some emotional support.

Everyone was so frightened and paranoid about the disease that these people were totally isolated and people in the hospitals were treating them terribly. Their families were frightened to death. No one knew what was going on. So Pete and I would go in, sometimes we'd try to talk with people's families and try to give them some encouragement. It was very unofficial. We certainly didn't do it with any titles, and we were only in contact with people who somehow heard about us, or maybe their medical provider heard of us. It was a word of mouth kind of thing.¹⁹

In July of 1983, Bill hosted a potluck dinner for a group of gay men. The purpose of the dinner was to create a forum in which gay men could share concerns and educate each other about AIDS. This event was the first of what became regular potluck dinner meetings. Often the meetings included guest speakers who dealt with AIDS in their work. This group met regularly for quite some time.

In November, 1984, a local educational organization sponsored the first public presentation on AIDS in Rhode Island at a hospital in Providence. At the end of the program, Bill circulated a sign-up sheet for those interested in working on local AIDS-related issues. At the time, Bill had no idea how he might use those names.

Several months later, in the spring of 1985, "John", a client of Bill's became very ill. John had previously lived in New York and upon discovering that he had AIDS, moved back to Rhode Island to be with his family. While in New York, John became familiar with the Gay Men's Health Crisis, an AIDS

organization in New York which offered extensive services for persons with AIDS. One day, Bill recalls, John sat down and said, "Look, one of the things that we really have to do is we have to have services here. I need them, and other people are going to need them behind me, and I really want to help to get that started." Using the people in the potluck dinner group and others in the gay community, as well as the list of names from the program on AIDS several months previous, Bill and John organized a grassroots meeting to establish a committee on AIDS in Rhode Island. It was set for May 31, 1985. This meeting was to become the first meeting of Rhode Island Project/AIDS.

There were twenty-eight people at the meeting. Of those twenty-eight, many were medical professionals. There were also a lot of gay men, including some from the Rhode Island Gay Men's Network. Also present was the mother of a person with AIDS. There were two speakers at the meeting: a man who was falsely diagnosed with AIDS several years earlier, and a holistic massage therapist. Afterwards, the floor was opened for discussion about the future needs of this newly-formed task force and about the formation of committees to address the state's AIDS crisis. The issues discussed included the need for a name, the need for money, and the recruitment of more members. Three committees were also formed: education/medical, direct services/mental health/clergy, and administrative/public relations/fundraising. Each committee was to meet separately in the following weeks, and a second organizational meeting was scheduled for a month later.

The next few months moved quickly for the group, which now called itself Rhode Island Project/AIDS. It was during this time that the Project defined its three goals: intervention to protect the state's blood supply, education to the medical community and to the public, and direct support services for those with AIDS or

AIDS-related complex (ARC). To accomplish these goals, three programs were created: the Hotline, the Speaker's Bureau, and the buddy Program. The Hotline would be a way for those at high risk, as well as others, to obtain accurate and straightforward AIDS information. This was partly seen as a way for those at possible risk to get facts about testing, high risk activities and risk reduction information. This way, it was reasoned, these individuals could assess their own risks and seek an HIV test if they chose to do so, instead of endangering the state's blood supply by simply donating blood to determine whether or not they had been exposed. The Speaker's Bureau would send trained volunteers to present AIDS information to groups of medical professionals, as well as other concerned professional, community, religious and school groups. The buddy Program would train volunteers who would then be assigned one-on-one to a person with AIDS or ARC. The buddy would then help that person in a number of ways, including getting benefits, emotional support and friendship, support to the person's family, and tasks such as feeding and cleaning up the person during the disease's late stages. In other words, a buddy was an educated, dedicated, protective friend to a dying person.

It should be noted that even before the group had come together, each of these programs had already existed on an informal basis. Bob Hitt and Bill Pellicio were already answering Hotline calls at their homes. Marge Stenberg had already made AIDS presentations to a number of medical and professional groups. And many people had found themselves thrust into the position of being a buddy, despite lack of training, when people close to them became ill.

All three of these programs were to be staffed by trained volunteers. In addition to being much less expensive to an organization than paid workers, volunteers would have a dedication and commitment that employees, precisely

because they are paid, could not have.

Besides the other programs, volunteers would also develop informational pamphlets targeted at those at high risk. The high percentage of cases related to I.V. drug use suggested the need for pamphlets targeted at drug users. Pamphlets could be an effective means of reaching this group because I.V. drug users are often hidden and hard to identify. This need alerted people involved in the initial founding of the Project that the input of former I.V. drug users was an important part of dealing with AIDS in the State.

To raise money to cover start-up expenses, the group placed donation cans in gay bars and gay-owned businesses. A hat was also passed at each Project meeting. Nine dollars was collected at the first meeting. This money went for things such as photocopying and postage.

The most important decision for the future of the group during these early months was whether or not to incorporate. Incorporation involved registering officially with the State and would allow the group to apply for grants and to operate as a not-for-profit organization. Additionally, once the organization was incorporated, it could then go on to obtain a 501C3 designation from the federal government, a long, drawn-out process which would allow the organization tax-free status. This would allow any private donations to the Project to be tax-deductable. The decision of whether or not to incorporate rested on whether the group was going to seriously pursue its goals into the future. If people were going to drop by the wayside, then incorporation was just a hassle. But if people were really dedicated, incorporation would allow the group to pursue grant money to operate, as well as an official title the group could use to build credibility. By the end of October it was apparent that the group was dedicated in its purpose. Rhode Island Project/AIDS was officially incorporated on September 16, 1985.

To incorporate, the Project had to elect officers. Linda Durand recalls, I heard through Bill Pellicio that there was a meeting trying to organize some people in meeting the needs of PWA's, people with ARC, and HIV positivity. So I went to a meeting....and at my first meeting, they thought that because I had an honest face I could be Treasurer.²⁰

It was just before incorporation that Marjorie Stenberg was elected President of Rhode Island Project/AIDS. Stenberg remembers that she was elected President for several reasons. First, she was not gay. This was important because she could reach people who otherwise would not deal seriously with someone who was gay. "It was mainly for public relations," she recalls.²¹ Second, the fact that she was a medical professional gave the organization credibility. Third, she and her husband had many strong social and political connections, having both been active in the civil rights and women's liberation movements in the sixties and seventies. These connections could be useful to the Project.

The Project Incorporates

After Rhode Island Project/AIDS had been officially incorporated, the organization had three primary needs. First was the need for office space and a telephone. Second was the need for people to write grants. Third and finally, people were needed to set up the buddy program.

While all of these things were important, it was clear that office space was the most urgent need. As things stood then, Rhode Island Project/AIDS was Bob Hitt's living room and a Providence post-office box. This issue was discussed during the very first meeting of the Project's newly-formed Board of Directors. A primary concern for the office space was safety. There would often be people

working alone on the Hotline at night. Marge Stenberg recalls that by September of 1985,

Although we did not wish to be a government agency, we were looking for space to be given to us by the government. One of the reasons we were doing this was because I had connections, through my son who works there, and through my husband, who later got work there writing speeches for the Governor. We thought about the safety in a [State building], We were concerned with the safety of renting. We knew we couldn't rent-we didn't have any money. But we needed office space to work out of right to begin with, and we needed our Hotline, our telephones. Those are the things we asked for [from the State] immediately. We also asked for some funding, but it wasn't the right time in the state's budget. We decided that the State building would be safe. The disadvantage of a State building was that we couldn't get in on weekends.²²

So the Project applied to the State for office space and telephones. However, time went by and nothing happened. Ken Fish, Vice President of the Board and Director of Support Services for the Project, recalls,

The Governor's Office had been talking about making a decision about allocating office space to the Project for several weeks, and it just wasn't happening. Either he was out of town or the right people weren't there. It seemed to be languishing in [the Governor's] Office. I told Bob that I knew some people in the Governor's Office, a fellow who was at that time the head of the Governor's Policy Office. Fred was a former student of mine in Cranston, and I used to be his swim coach in addition. So the next day I walked over to the State House, knocked on his door and said, 'Hello, Fred. Do you remember me?' 'Oh, Hello, Mr. Fish! I haven't seen you in years!' We closed the door and I said 'Listen, Fred. This is what I want. Tell my why is this stuck and what will it take to get it moving?'²³

Several weeks later, Rhode Island Project/AIDS was allocated a small office and

telephones. The Project moved into the space in February of 1986.

The need for a grant writer was fulfilled when a member of the Project's Board of Directors asked her friend Tom Martin, who was an experienced grant writer, to help with fundraising. Because he was concerned about the AIDS crisis and because of dedication to his friends on the Project's Board of Directors, Tom agreed to volunteer some time to the Project. Tom recalls that,

...the whole idea was basically to do some training for the members of the Board, who would later follow up with other grant writing. We finally decided just to submit one, to the Rhode Island Foundation. That was the result of making some contacts with the Director of [the foundation] and finding that he had a real interest in supporting the idea. We went through the process, nonetheless, of grant writing, and many of the individuals on the Board were, I hope, then prepared to write grants.²⁴

In fact, in the spring of 1986, Rhode Island Project/AIDS received a grant of \$35,000 from the Rhode Island Foundation. The grant covered basic start-up costs for the organization, including the printing of brochures and would also be used to hire a full-time Executive Director.

Once the office space was secured, Ken Fish was ready to get the buddy program started. One problem was figuring out how a buddy should be trained. Ken realized that he himself needed to be trained. So, in February of 1986, Ken and two other volunteers with the Project, Gordon and Bernie, went up to Boston and participated in the AIDS Action Committee's buddy training program. The training, which included listening exercises, lessons on how to feed someone, and information on how to negotiate getting benefits or legal advice for someone, as well as the basic epidemiology of the disease itself, served as a model for the buddy training at Rhode Island Project/AIDS. The next question was how to get volunteers to become buddies. At first, Ken simply encouraged people who were involved in

other areas of the Project to become buddies. This became less necessary as more people learned about the Project and as more people's lives became affected by the disease.

The growth and success of Rhode Island Project/AIDS has been truly remarkable. Just over two years after being incorporated, the Project is now run by two paid staffmembers and over 200 volunteers of varied races, religions, and backgrounds. The Hotline currently receives about 600 calls per month from men and women, heterosexuals, bisexuals and homosexuals of all traits and ages, concerning information on issues such as prevention, testing, transmission, and symptoms. The buddy program has also grown rapidly, adding a direct services fund to provide limited emergency financial assistance for PWA's. This fund accounted for 15% of the Project's 1986 budget, and will likely grow in the future.

Given the fact that only two years ago, twenty-eight people were passing a hat around someone's living room, how did the Project ever succeed? There were three primary reasons. The first reason was the fact that the Project was a coalition. Second was the fact that the Project was run by volunteers. The third reason was the Project's successful use of networking.

The primary reason for the success of Rhode Island Project/AIDS was that it was a unique coalition of two very different communities, namely gays and health care professionals. If the Project had been started by either one of these groups and not both, it would have quickly failed. Veneita Porter, the Project's Executive Director, agrees that coalition of diverse groups adds great strength to a new organization:

It is essential that newly-formed organizations go for the broadest-based citizenry possible. Many organizations find themselves labeled, sometimes falsely, so presenting a diverse face to the public is important. Leadership among women and people of color must be nurtured in order

to obtain continuing dialogue with these communities.²⁵

If a group entirely composed of medical professionals had started the organization, they would have lacked a crucial element: an entry into the gay population.

Without knowledge about or trust from the gay community, the groups efforts would have been misdirected and ignored. Likewise, if a group composed entirely of gay men and women had started the organization, it would probably never have gotten either media attention or grant money. Worse, it would never have gotten the trust of the medical community. Without this trust, AIDS patients would never be referred to the buddy program, as is the primary means of connecting buddies with people with AIDS. Ken Fish recognizes

"...the importance of the increasing acceptance of the Project as a viable support mechanism within the broader community of the State....and the credibility of the agency among referring-type agencies such as doctors and nurses and clinics and hospitals. The typical referral takes place when a health care professional suggest to a potential client that they have some needs the Project could satisfy, and why not check it out. That initiates a call to the Project or to me directly, and I then make contact with the person and I say 'Do you really want to talk to us?' If they say yes then I go and talk to them. That initial conversation usually takes about an hour and a half long....I explain what the Project is and does and suggest ways we might be of assistance to them."²⁶

Bernie, one of the first buddies with the Project, recalls that even as a partly medical coalition, the Project had troubles overcoming suspicion on the part of physicians, as well as overcoming the stereotype of being a gay organization.

The second reason for the Project's success was the fact that it was run by volunteers ensured that those involved were compassionate and dedicated. Ken Fish feels that governments and business interests aren't well set-up to provide for the personal and psychosocial needs of people with AIDS.

They don't have the resources, and we do have those resources. We've been able to stimulate those resources from within our community, and redirect them and organize them to support the needs of the people that are infected within the community.²⁷

Bernie agrees. "They [the PWA's] become your friend. They confide things in you they wouldn't confide with anyone else." Bernie's dedication to the care of people with AIDS is obvious; he's been officially assigned three times, and he carries special memories of each person he's served as a buddy. Moreover, being a buddy is a big responsibility and a heavy time commitment. If your PWA needs you and you're at work, you simply have to leave work. The first PWA assigned to Bernie, "Steven", was a former drug addict who was infected from sharing an intravenous needle. While Steven already had a buddy, he was now in pretty bad shape, and so Bernie was assigned to co-buddy. Bernie recalls,

When I was assigned to [Steven], Cheryl was already working with him. He was getting so weak, and she was afraid that when she took him out that he would fall and she wouldn't be able to handle him. So I was assigned with him as a co-buddy....It was quite a new experience for me because he was blind at the time. I would go in and say stupid things like "can you see this..."; and I'd forget he was blind....He got progressively worse and passed away in October of 1986. His mother took it really hard.²⁸

Although her son died over a year ago, Bernie is still in close touch with Steven's mother. He has coffee with her now and then, and he reminisces with her and helps her grieve. Bernie is close to other former PWA's loved ones, too.

Ellen Moreno, a social worker with the Project sees the importance of the buddy-PWA relationship being a personal one. In one situation, Moreno

remembers a buddy intervening in an argument between a PWA and his landlord. Another time, when a PWA was no longer able to cook for himself, the buddy was there to cook every meal. In another situation, ...a buddy and I were able to talk to a family about not continuing or deciding upon life support measures....The buddy was able to work with me and the family to come to the decision about not prolonging the patient's life."²⁹ Linda Durand also sees the personal connection between buddy and PWA. In one instance, a PWA came to her office, her child with her, for a routine test. A surprisingly bad result came up, and the woman had to be admitted on the spot. Linda simply called the Project, and the woman's buddy came by to pick up the woman's child, picked up the woman's older child from school, and brought the two home. In another instance, the patient

...was new to the State. He was very ill, and I had to admit him on the first visit. His buddy came with him, and was there to hold his hand for the whole visit. He was just there for support. He stayed with him and walked him through the whole process, right up to his hospital room, stayed with him there until he got settled.³⁰

The philosophy of Rhode Island Project/AIDS comprehends that this type of a relationship between buddy and PWA could not be achieved unless it were totally voluntary and based on compassion.

The third reason for the Project's success was that it was built on personal connections of those already involved. Rhode Island is the smallest of the fifty States, so it was relatively easy for a group like the Project to make their presence known there. Additionally, Rhode Island's "small-State mentality" results in great resources from people's personal ties. New volunteers for the Project were often friends or loved ones of a client of the Project or friends of old volunteers. Most of the personal contributions to the Project came from people whose friends and loved

ones had been affected by AIDS. The Project built its list of referrals by using connections. The need for connections is of such importance that the Project hired Veneita Porter, a Black woman, as Executive Director in summer of 1986. Veneita's job consisted mainly of networking with other individuals and agencies and the State. Due partly to Veneita's work the Project now has contacts in both the welfare and SSI offices that have helped smooth the process of getting benefits for person with AIDS. The Project also now has contacts for legal advice, hair cutting, dentistry, counseling, and massage. Marge Stenberg remembers getting a positive response after presenting some information on AIDS to a group of Rhode Island funeral directors in 1985:

One of the major problems we had was funerals for AIDS patients. We couldn't get people to offer funerals for them. There were people who said that you needed to have a lead-lined casket to put them in. There was a funeral home that said, we won't enbalm this person. We have to send this body to Boston to get enbalmmed. It will cost you \$1000.³¹

After Stenberg spoke, several funeral directors came up afterwards and told her that they would be willing to perform service for people who died from AIDS. The majority of the Project's growth was due to networking, according to Ken Fish,

A lot it is networking. They are friends of friends. They are people that we know who work in that field and we ask for assistance. Or sometimes there are people in that field who come to us and say 'I want to be involved, I want to help. How can I help?' If they happen to work for SSI, there's a specific way they can help that others cannot help. We also get people in because I ask them to help with the buddy training. If they come in and do a buddy training, they come and meet what buddies are like, and then they are much more amenable to assistance in other ways. As we have more and more people involved in the service as volunteers, they have more and more friends. Sometimes its relatives and friends of people who are affected by the illness-the lover who's left behind, the

brother of a PWA....Sometimes after the death of a client, some of those people want to pay back, repay some of the support they have received by the Project by providing that support to others.³²

Networking among the professional community was crucial to the operation of the buddy program. The coordination of external service providers is an ongoing process for the Project. In the past year the Project has started surveys on three groups of caregivers: physicians, mental health agencies, and dentists. The results of these surveys should get a more realistic perspective of the providers' attitudes, increase the actual number of referral sources for the Project, and alert providers in the community of the existence and activities of the Project.

In summary, Rhode Island Project/AIDS grew from the rare atmosphere of an effort share by two concerned communities. However, the Project's success doesn't preclude the presence of factors such as luck. Indeed, the Project was quite lucky to find such dedicated people to work directly with persons. For example, Ken Fish puts in between forty and sixty hours of volunteer work for the Project per week while holding down a full-time job at the same time. "The Project work," he states, "is what I do. My job is what pays my salary and pays the bills."³³ Linda Durand overcame her own fears to deal with AIDS patients back in 1983. Linda feels that it's often difficult "...to maintain an attachment so you can remain therapeutic...I've cried with patients. I've responded the same way they've done with news, with anger..."³⁴

Although many issues surrounding AIDS, such as widespread AIDS education and HIV testing were certainly public, others such as care of those stricken was more private in nature. Due to the controversy over the issues of sex, homosexuality, condoms, and intravenous drugs, the public was initially unable to respond even to those public needs. The Project arose to tackle both the private

issues of AIDS and those public issues left unfulfilled by the State. It is interesting to note that, while the Project often serves as consultant or as political lobbyist, the State government has now itself begun to finally deal with the public side of AIDS, instituting an educational program in the schools. But the effectiveness with which Rhode Island Project/AIDS has dealt with the human aspects of the State's health crisis have been recognized even in the State House, which designated a \$50,000 State appropriation to the Project in mid-1987. This money, two years after the organization's incorporation, was the first government money received by the Project.

It is likely that the State will continue to assume responsibility for the public sphere of AIDS in the future. However, the Project's future is not in jeopardy. The Project still serves as a consultant for the State and its dealings with AIDS. Additionally, the Project still provides a rare access to the State's gay community. Third, with AIDS cases doubling every six to nine months³⁵, there will be private AIDS needs for a long time to come. Volunteers I talked to expect that the Project's services will expand, perhaps into housing for PWA's. Others envision an expanded consulting role to government and private business through methods such as conferences. One such conference is already planned for January, 1988. The first of its kind in New England, the conference will focus on AIDS in the workplace.

To continue to meet the continued personal needs of people affected by AIDS, the Project hopes to increase its base of support in the State. One problem lies in the fact that most of the AIDS cases in the past have been in Providence County. This has allowed people in outlying communities to ignore the problem. But AIDS has become more prevalent in the outlying counties recently. "Because Rhode Islanders in general seem to feel that driving more than 15 or 20 minutes is a

major undertaking," Veneita Porter commented, " the Project intends to sponsor volunteer training in the outlying areas for the Hotline and the buddy program."³⁶ Indeed, one characteristic that typifies Rhode Island is that although you can drive across the State in an hour, many of the State's communities are physically isolated. For example, according to Porter, "...Newport residents have for years ignored the problem of AIDS by rationalizing that the virus has not hit the island yet. It has been a process of evolution getting these isolated communities more involved."³⁷

Another of the Project's concerns for the future is money. Rhode Island is a difficult State to raise funds in because there are less than a half dozen possible grant makers in the State. Of these, only two have shown any interest in the Project. The Project's Rhode Island Foundation grant was only a three-year start-up grant, meaning that this funding will end soon. Other granting sources have been slow to respond. The Project's fundraisers are concerned over the lack of funding resources and consequently are seriously considering the possibility of direct mail solicitation as a source of income. Community fundraising events will also hopefully play a larger role in the future of the Project. A board member comments that "...initially, the gay community was slow to accept financial responsibility. But in the past year this has changed."³⁸ One example is the Rhode Island Gay Men's Network, which has already agreed to organize a large contingent for an important upcoming Statewide fundraising event.

The foundation of an organization such as Rhode Island Project/AIDS is usually a lengthy, complicated, and frustrating process. Several of the Project's board members felt that the most important factor of the Project's success was getting committed, charismatic people. For Rhode Island Project/AIDS, the warm, outgoing personalities of these rare people proved invaluable in networking with other individuals. Others with the Project stressed the importance of including

members of all affected groups. While acknowledging the difficulty of reaching I.V. drug users, these people felt that incorporating sufficient representation from the I.V. drug user community should be one of the Project's goals for the near future.

From her own experiences, Veneita Porter sees a need for new organization to be cautious in dealing with the media. The media has behaved somewhat unscrupulously in several instances in the Project's past. Linda Durand recalls that, while she was treating one of the State's first AIDS patients in 1983, a local media representative called her and offered her money in exchange for the patient's name. In other instances, the context of remarks made by Project representatives had been manipulated. The possibility of getting biased, bad press makes it necessary for the organization to plan its goals and expectations of the media in advance: "It's difficult not to be manipulated by the media, but not impossible."³⁹

Finally, the leaders of a new organization need to have realistic expectations of growth. Fast expansion, which is common among AIDS-related organizations, will take a toll, especially on the organization's founding members. This was certainly the case with Rhode Island Project/AIDS, as only a fraction of the initial founders are still involved. Ken Fish sees this as a natural phenomenon for community organizations:

People come together around an issue, but they have a lot of specific ways in which they would like to approach that issue. As the group dynamic proceeds and the group forms a direction, it's not compatible with the vision of some of those people, and they drop by the wayside, sometimes quietly, sometimes raucously and squawking.⁴⁰

Outside consultation can be helpful in managing this growth process.

When asked if he saw the Project as a success, Tom Martin replied, "Rhode Island Project/AIDS amazes me in the sense that I've looked at others and that it is one of the better organized, more thoughtful groups. It is surprising that a group so young has done so well."⁴¹ Indeed, the history of Rhode Island Project/AIDS is truly a remarkable one. As a newly formed coalition, the Project set out to deal with a public and private crisis of massive proportions, and with virtually no money. Within all the people at Rhode Island Project/AIDS lies the hope that one day AIDS will be cured. When that day finally comes, the people behind the Project should be recorded as true heroes who served their fellow Rhode Islanders in a time of crisis.

Endnotes

- ¹ Wayne Worcester, "State, Gay Task Force to Hold AIDS Workshops," *The Providence Journal*, 21 June 1983, p. A1.
- ² C. Eugene Emery, Jr., "R.I. Officials Confirm 1st Death Due to AIDS," *The Providence Journal*, 21 September 1983, p. A2.
- ³ *The Providence Journal*, "2nd Rhode Islander Dies of AIDS," 18 October 1983, P. A1.
- ⁴ *The Providence Journal*, "2nd Rhode Islander Dies of AIDS," 18 October 1983, P. A1.
- ⁵ Marjorie Stenberg, personal interview, November 8, 1987.
- ⁶ Marjorie Stenberg, personal interview, November 8, 1987.
- ⁷ C. Eugene Emery, Jr., "A Death in the Family," *The Providence Journal*, 4 December 1983, p. A1.
- ⁸ Bob Hitt, personal interview, October 28, 1987.
- ⁹ Ken Fish, personal interview, October 25, 1987.
- ¹⁰ Tom Martin, telephone interview, November 8, 1987.
- ¹¹ Bob Hitt, personal interview, October 28, 1987.
- ¹² *The Advocate*, November 10, 1987, p. 41.
- ¹³ *The Advocate*, December 23, 1986, p. 25.
- ¹⁴ *The Advocate*, March 7, 1987, p. 15.
- ¹⁵ Veneita Porter, personal interview, December 8, 1987.
- ¹⁶ Linda Durand, personal interview, November 9, 1987.
- ¹⁷ Ellen Moreno, personal interview, November 9, 1987.
- ¹⁸ Bill Pellicio, personal interview, November 7, 1987.
- ¹⁹ Bill Pellicio, personal interview, November 7, 1987.
- ²⁰ Linda Durand, personal interview, November 9, 1987.
- ²¹ Marjorie Stenberg, personal interview, November 8, 1987.
- ²² Marjorie Stenberg, personal interview, November 8, 1987.
- ²³ Ken Fish, personal interview, October 25, 1987.
- ²⁴ Tom Martin, telephone interview, November 8, 1987.
- ²⁵ Veneita Porter, personal interview, December 8, 1987.
- ²⁶ Ken Fish, personal interview, October 25, 1987.

