La Corporation Félix Hubert d'Hérelle

Annual Activity Report
1996 - 1997

Félix-Hubert d'Hérelle Corporation

Cover page illustration
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The Félix-Hubert d'Hérelle Corporation is a non-profit organization created thanks to an initiative of the Ministry of Health and Social Services, the City of Montreal and Centraide.

La Maison d'Hérelle is a community residence for people living with HIV/Aids, experiencing loss of autonomy.

Its objectives

- To offer an adapted living environment to people living with HIV/aids;
- To provide appropriate care and services to residents;
- To encourage autonomy and active participation of the resident to his or her quality of life;

- To provide support to families and friends.

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Foreword from the President

La Maison d'Hérelle : a new beginning

An annual report on finances and activities is, in itself, an ordinary document. However, for us at d'Hérelle, this seventh annual report has special significance because it has entitled us to glance back at the road traveled thus far through the years. In fact, this report, with the acquisition of the building at 3742 St. Hubert, its renovation, its establishment and its new occupation, constitute a new beginning and the start of a new era: la Maison d'Hérelle Phase II.

It is also an opportunity to underline several important anniversaries.

To begin with, it was ten years ago this year that was brought forth, at the Hôtel-Dieu Hospital in Montreal, the idea of a residence for people living with HIV. It was in May 1987 that Mrs. Saloi Eid, a social worker whom we had convinced to handle aids patients in priority and who ended up handling almost exclusively the Hôtel-Dieu's aids cases, walked into my office and declared her intention to setup a community residence capable of taking into account the specific social and economical problems related to this new illness, to offer a sympathetic and warm setting and to provide appropriate care to its residence: it was dubbed Project Salamandre.

After two years of preparation, scheming, negotiating and I dare say hesitating (which in fact had the better of Mrs. Eid's patience), the concept for la Maison d'Hérelle nonetheless came to fruition, on paper at least, in May 1989. It was a relatively complex project which was to include the financial collaboration of the Quebec Ministry of Health, the City of Montreal and Centraide. This three part agreement allowed us to go ahead with our project which, by the same token, was granted a new mission: to serve as a functional pilot project and model resource. So much work, so

much effort, so many steps, but so much joy too, went into this achievement, where people living with HIV remained at the core of preoccupations for all that were involved. It was truly because of admirable work, often in difficult conditions and with limited resources, that the initial, pioneering team was able to setup this first residence: what we refer today as la Maison d'Hérelle Phase 1 and which welcomed its first resident in May 1990.

Since 1994, faced with increasing demand for its services from new cases, the idea for expansion and the addition of a second residence emerged from the executive council. So many steps to follow, so many meetings, so many negotiations and so much energy was spent in order to hold, on May 8th of this year, the official opening of a second house with six new places for residents, improved community living with more appropriate quarters, where residents living with HIV may retain their individuality and remain the focus of all the care.

It is with tremendous pride and much gratitude that I would like to extend my thanks to those who have enabled us to celebrate the event which brings us together today: the official opening of our second residence and the beginning of a new phase, la Maison d'Hérelle Phase II.

As I pointed out, there have been, there are and there always will be some problems at d'Hérelle, but the quality of the teams in place, implicating just as much the residents, the employees, the volunteers, the executive council and the Board of Directors have surmounted them and have helped create a warm place to live, a place bristling and alive with activity, focused on life and the human person; a place where one may live, but also die, in peace, dignity and compassion.

I have to say that these days, community residences face outstanding challenges: where are the headed? Will they survive? The current trend is to economize, financial backing disappears without warning. Furthermore, to speak of aids is neither popular nor fashionable media, quite the contrary, it seems the subject must be avoided. But meanwhile, the epidemic progresses, no matter what we do. Statistics are revealing and HIV remains the number one health risk worldwide for the World Health Organization. If certain attitudes have changed in regards to aids, this illness remains

marginalizing, with accompanying social and economical consequences. Of course, thankfully, there are new therapies which are perceived by some as a panacea which is on the way to solve the problems of aids. However, the fact that patients come out earlier and earlier from hospitals and the fact that fewer spaces are available there for them, these patients require much more care from community resources than in the past. Furthermore, the clientele is changing: women infected with HIV experience loss of autonomy are more and more numerous and they bring a new angle to the care required, the number of drug users infected with HIV has increased in an unprecedented fashion and finally, the number of homeless people infected has increased dramatically. But in fact, what are the long term benefits of the new medications which, in certain cases, offer spectacular results? We simply don't know. But this fact did not stop an optimistic technocrat to declare recently that the need for resident care will diminish as a result and that fewer and fewer beds will be required...! Unfortunately, I must reply that we must certainly not be on the same planet...

As far as la Maison d'Hérelle Phase II is concerned, as we have done during the course of the initial phase, we shall have to adapt and accept to live with the changes and adjustments, all the while pursuing the ideals which we have challenged ourselves with, and which will have to be maintained and preserved in the future. With the outstanding multidisciplined teams which have gathered around the residents of d'Hérelle, including the patients themselves, their family and friends, the volunteers and staff, the members of the administrative council and the Board of Directors, we are prepared to meet the future with guarded optimism, but mostly with maturity. And I dare say that the future, with the addition of this second residence, promises to be interesting. We should be able to pursue our triple-faceted mission, namely: 1. to offer a warm, serene, compassionate place to live for our residents, 2. to provide physical care as well as social and psychological support required by the very ill and finally, 3. to meet the demonstrative challenges of our mission and continue to be a model resource for other residences.

In regards to this demonstrative aspect, we should note that once again this year, we have contributed to the instruction of trainees from other community residences, we have acted as a reference for new projects, we have initiated new partnerships with other organizations and existing residences in the Montreal region and finally, we even

collaborated in the staff training of a community resource for children living with aids in Haïti. Furthermore our statistics, which are regularly compiled and analyzed, will be the object of presentations, publications and further conveyance. Financially, we will emphasize the substantial savings incurred by the state through its continued support of la Maison d'Hérelle.

In closing, I would like to thank and stress the remarkable role of our Executive Director Mrs. Michèle Blanchard, who has managed all year round not only to see to day to day business, but has also taken an active part in securing finance for the residence, in harmonizing relations with other projects and has played an active part in establishing the influence of la Maison d'Hérelle.

I must finally mention the discreet yet so crucial functions of the Board of Directors in the life of the residence. It is a fact that we are not as present as other groups, but I wish to emphasize the level of implication and the seriousness which has been dedicated to the task by each member. Board members come from varied backgrounds and contribute unique expertise and experience. Each and everyone has dedicated some precious time, this year in particular, in order that the second residence project be a successful endeavour, realized within the tight constraints of the project budget. I wish to thank each member for their contribution and collaboration.

In my name, in the name of our Executive Director and the Board of Directors, I invite each of you to get involved in the activities of la Maison d'Hérelle Phase II, be it through your simple presence, your ideas, your suggestions or your donations, which are of course, always indispensable.

Richard Morisset, MD, M.Sc. O.C.
Professor, University of Montreal

Foreword from the Executive Director

To sum up the year is no small feat! This report seems somewhat splintered considering the various steps which we have experienced with the achievement of «Phase II», the enlargement and renovation of the residence. However, life seems to have followed its course around our residents who witnessed the experience, along with those who gravitate around them on a day to day basis.

It was a considerable challenge to pursue our work and stay on course with the project! So many questions, so many surprises and unforeseen events. How to plan a strategy, with whom and with what means to endure living and working on a construction site? How to adequately pursue our activities, on top of those expected with the return to the new household? And all this with the required composure and harmony!!!

Inevitably, questions are answered and the plot runs its course, thanks to all the collective efforts. Back home since the 5th of December, all of us are assuming our space, getting used to the new quarters and making the necessary adjustments. Each in their own way, yet collectively, even if sometimes we wonder what the next day will bring!

To be able to welcome six additional residents was a long time goal of the Board of Directors. We understand the changes and the evolution of Aids, this reality is already

felt in the residence. But we are aware that the challenge is well worth it because we know the results are incredibly powerful.

Indeed, everything comes together when faces and events combine, with significant gestures and actions, with shared uncertainties and, of course, with the inevitable confrontations. Faces which have been etched in my mind and have become part of d'Hérelle's short history. We will not forget the departures, residents who have passed on during the voyage...and members of the team who have called on other shores. Among these is Dr. Louise Lessard who has left us after six years, replaced in the changing of the guards by Dr. Peter Blusanovics.

I wish to thank the members of the Board of Directors, who have earned my esteem and admiration for their enlightened input in key moments, and for their deep individual commitment.

My thanks to the residents and their loved ones, who on top of their day to day struggles, have had to endure this adventure and put their faith in us. To the staff and volunteers, for their discreet acts of solidarity that often go unnoticed.

A special thanks to the nuns of the Communauté Religieuse des Soeurs de la Providence, for their warm welcome during this transition period; to the construction committee and donors, who have made this dream into reality.

May you read this report in the light of these contributions and experience some of those little extravagances that inhabits us all.

Pleasant reading.

Michèle Blanchard

1. Profile of the clientele

May be admitted at la Maison d'Hérelle any person living with HIV/Aids, who is experiencing loss of autonomy, requires housing and support and this, without any form of discrimination.

Specific criteria

- To be unable, by oneself or with the help of close ones, to meet one's needs and to live in one's customary environment;
- To be unable to gain access to sufficient services in order to remain at home;
- To require adapted domestic facilities;
- To undertake to respect rules of participation and community living.

Since December 5th 1996, la Maison d'Hérelle is capable of welcoming 17 persons: 16 beds are allotted to people petitioning for residency (long term care) and 1 bed is reserved for persons in need of short term assistance (short term care).

Since the opening of la Maison d'Hérelle in May 1990, we have welcomed over 150 residents.

The following pages contain:

- a chart presenting statistical figures reflecting the last two years of operations (1995 - 1996 and 1996 - 1997) and cumulative data from opening (1990 - 1997);

- an overview of the evolution of the clientele;

- a chart presenting figures relative to admission requests;

- a description of services offered to friends and families of residents.

Evolution of the clientele

Analysis of figures observed from the residents' profiles, between 1990 and 1997, warrant a number of observations.

Age upon admission

We note that the average age upon admission has slightly diminished:

- 38 years, this year (1996 - 1997) ;
- 41 years, last year (1995 - 1996) ;
- 38,8 years, since opening (1990 - 1997).

Sex

Since opening in May 1990, la Maison d'Hérelle has welcomed a large majority of males, nearly 97% in seven years. This year, 20% of our clientele was female.

Type of care

In preparation for Phase II and the relocation of residents for the duration of the renovation work, we had asked our referring services to give priority to petitions for short term care and suspend until reopening of the resource, in December 1996, petitions for long term care. Therefore this year, 40% of our residents were admitted in short term care.

Hospitalizations during care period

Despite obvious lengthening of the terminal phase, a rise in neurologically linked disorders and the appearance of new symptoms, residents are rarely hospitalized during their stay at la Maison d'Hérelle. This year, 84% of residents were not hospitalized at all and 12% were hospitalized once.

Length of care period

In seven years, the longest care period has been 1609 days, or 4 years and 5 months. This specific case resulted in a rise in the average care period figures this year to 6.4 months. The shortest stay was one day (short term assistance).

Place of death

During the course of its first two years of existence, fewer than 73% of residents passed away at la Maison. More than 92% have died here in the last five years and this year, 100% of residents who died remained at la Maison d'Hérelle until the end of their life.

Associated disorders

In the last four to five years, we have witnessed a significant rise in various symptoms and new afflictions :

RISE IN AFFLICTIONS

- Herpes
- Neurological disorders
- Mental health disorders
- Toxoplasmosis
- Zona

OTHER AFFLICTIONS

- Cytomegalovirus (C.M.V.)
- Mycobacteriumavium (M.A.I.)
- Cryptococcus
- Convulsions

We note that it is often difficult to determine whether certain symptoms are related to neurological disorders or mental health related problems. This year in particular, we observed a significant rise in the drug-addicted clientele: nearly 40% of residents were included in this category.

Note: This year, we propose a detailed list of associated disorders in order to better identify the care required by the clientele we shall welcome during the course of Phase II. A chart of associated disorders encountered in previous years can be found in annex.

Support for friends and family

Our clientele includes close ones of residents, families and friends. Below are the services offered to them and the number of persons who took advantage of them:

Nb of persons	Service
74	**Psychological support** allows close ones to express emotions related to accompaniment and eventual loss of their loved one, as well as going through mourning.
46	**Information regarding the progression of the illness** allows better comprehension of the physical and psychological effects on the sufferer, for those who are unfamiliar with the afflictions related to the progress of Aids.
24	**Advice regarding care and pain management** offers loved ones the opportunity to become familiar with the required care that must be administered to ensure the comfort of the person living with aids, and it is a chance for them to establish intimate contacts, particularly during the course of the final phase of the illness.
11	**Alternative approaches to health management** are also offered to loved ones of residents. They include, namely, massages, natural medicines with relaxing virtues, aimed at reducing stress and anxiety.
11	**Legal and para-legal support** is aimed at assisting loved ones in their search for legal information regarding defense of rights or testamentary considerations.

8	**Medical support and information** is available thanks to regular weekly visits by a physician from a local community clinic, the St-Louis-du-Parc CLSC, who willingly offers such information to those who request it.
3	**Spiritual guidance** is offered to those who wish for companionship on their inward voyage, either in preparation for the loss of their loved one or during the first months of mourning.

Other services offered

On occasion, support meetings are offered to family and friends or spontaneously requested by them. These gatherings allow close ones to convene with a worker, to be informed on the resident's health status and to share their apprehension.

Each year, a commemorative evening is held to which are convened friends and families of residents who have passed away during the course of the year.

Staff presence at funeral services and other ceremonies are an integral part or the support offered by staff of la Maison d'Hérelle.

Day to day moments, around a coffee table, in the living room or during meals, are yet another albeit discreet manner, in which support is offered, which is non-negligible.

2. Volunteering

Expansion of la Maison d'Hérelle this year required a great number of adjustments in all spheres of activity, including the volunteering. Volunteer intervention had to be restricted during the course of the temporary displacement of residents, in order

to preserve ensure their intimacy in limited living quarters. However, this situation provided an opportunity for us to prepare for the upcoming changes.

The objective was to increase volunteer effectives and restructure the volunteering program to adapt it to a larger number of residents, while maintaining the individualized approach to care.

Since financial resources did not allow us to double the number of permanent staff, we had to ensure that the number of volunteers was increased according to a larger demand for services. Thus the number of hours was increased and training and pairing was organized differently.

From the onset of Phase II, seasoned volunteers quickly understood that la Maison d'Hérelle was not an expanded residence, but an altogether new project, and each had to review their commitment to the team. Thankfully, in large part due to individual contribution and collaboration, almost all our volunteers have managed to adjust to their new responsibilities and have remained on board.

Special thanks go to the great number of volunteers who participated generously in the building of Phase II: one resident took part in the weekly meetings of the construction committee, 40 people, including paid staff, provided innumerable hours during the course of three week-ends, to complete the painting work. One volunteer welcomed all the residents to his home for an entire day while personal effects were being moved, others assisted residents in reintegrating their rooms, an entire team was formed to decorate the house. And these are but a few examples.

The future of the volunteer program is difficult to envision. The impact of the health reform concerning the cost of medication is already being felt and certain changes can be noted in residents with the effect of tri-therapy, such that some are wondering is aids may some day be categorized as a chronic disease. On the other hand, the lack of financial resources is obvious in other aids resources and la Maison d'Hérelle, conscious of her expertise in volunteer management developed over the years, will strive to share her knowledge, namely with the publication of a volunteer guide book.

Hence during the course of the coming year, efforts will be made to increase to training of volunteers and strive to make the appropriate adjustments.

Volunteering statistics

Sector	Nb of persons	%	Nb of hours	%
Management	13	4%	956	4%
Alternative approaches	16	5%	1,872	7%
Others	180	53%	3,527	13%
Board of Directors	12	4%	991	4%
Consultants	7	2%	444	2%
Food services	19	6%	1,112	4%
Intervention	40	12%	6,470	24%
Personnel	31	9%	4,388	16%
Subsidized programs	7	2%	4,500	17%
Residents	4	1%	386	1%
Trainees (students)	12	4%	2,079	8%
Total	**341**	**100%**	**26,725**	####

Scope of activities of volunteers

1. Board of Directors
2. Assistance to the workers: general help, hygiene care
3. Vigil and attendance
4. Alternative approaches to health management: massotherapy, reiki, therapeutic touch, phytotherapy, aromatherapy, musical therapy, visualization, zootherapy, etc.
5. Socio-cultural activities: planning and organizing, ticket sales, music, etc.
6. Kitchen assistance
7. Nutrition and healthy eating
8. Reading
9. Fund raising

10. Admissions: organization and interviewing
11. Reception
12. Accounting
13. Software analysis and concept
14. Painting
15. Repairs and renovations
16. In-house journal
17. Hair dressing and grooming
18. Sewing
19. Legal care: lawyers and notaries
20. Attendance on committees and meetings
21. In-house general assistance
22. Outside assistance (medical appointments)
23. Follow-up assistance
24. Assistance to family and friends
25. Voice choir
26. Grafting drafting
27. Publicity design
28. Assistance to trainees
29. Transmission and representation: training in other resources, representation before federal and provincial authorities, health care networks, community networks and partnerships
30. Pairing
31. Training

Professional training proposed to volunteers

Once again this year, nearly 20 volunteers participated in training offered by the resource. The training sessions last 20 hours and offer the following themes:

- Social aspects of aids
- Death and spirituality
- Psychological aspects of the illness
- Personal care of persons living with HIV/aids
- Personal assistance of friends and families of persons living with HIV/aids
- Alternative approaches to health care
- Ethics and law

Volunteers who participate in comfort and hygiene care for residents are required to attend training on biomedical matters outside la Maison d'Hérelle.

Practical training is ensured by workers through supervision and pairing of new volunteers with experienced ones.

Variations in the clientele have coincided with the expansion of the residence and has prompted an increase in training appointments for volunteers in the coming year, in order to prepare everyone for the multifaceted challenges of alcoholism, drug addictions and mental health disorders.

3. The pilot project mission

Trainees at la Maison d'Hérelle

Following is an outlook of training offered this year:

Sector	Nb de persons	Hours
Nursing	4	1 003
Aids/HIV	2	160
Care workers	2	70
Specialized training	1	352
Social work	1	192
Psychology	1	120
Communication and psychosociology	1	110
Total	12	2 007

Trainees in subsidized programs

Intervention	4	2 730
Reception and secretarial	3	1 770
Total	7	4 500

Training offered by the staff

Our responsibilities as a pilot project has prompted us to share our acquired experience with other resources. Some of the vehicles for this endeavour have been training sessions and courses, workshops and conferences:

Date	Themes and organizations	Participants	Time
May '96	Aids residences Quebec-Wales Agency	2 nurses	2 h.
May '96	Basic training Maison d'Hérelle	16 volunteers, trainees & staff	20 h.
May '96	Conference: «Experience of community aids residences in Quebec» VIth Annual Congress of the Quebec Palliative Care Association	30 participants	2 h.
Sept '96	Conference: «Palliative care approach in aids residences» XIth Annual Congress on Palliative Care	30 participants	2 h.
Oct '96	Staff intervention training Aids residence Belgium - Namur	1 nurse	2 h.
Nov '96	Conference-workshop: «Aroma therapy in palliative care » Montreal South-West Sector Palliative Care Consortium:	55 participants	1,5 h.

«Team work in palliative care»

Date	Themes and organizations	Participants	Time
Jan '97	Conference-workshop: «Palliative care at la Maison d'Hérelle» Theme «To die at home»	35 participants	1 h.
Mar '97	Information on alternative approaches to health care Centre Hospitalier de Granby	1 nurse	3 h.
Mar '97	Training: «Pain management» ABAAPAS	20 participants volunteers and patients	3 h.
Mar '97	Training: «Palliative care in aids residences» Group from China organized by Notre-Dame Hospital social workers	1 physician 2 nurses	2 h.

Training received by the staff

In order to increase our understanding of various disorders related to aids and to keep abreast of the evolution of the illness, the staff attend training sessions, workshops and conferences for the exchange of this information. We also make great use and benefit greatly from internal resources available to us as well as the expertise and experience of individual staff members.

Date	Themes and organizations	Participants	Time
April '96	Conference on zootherapy	2 staff	1 day
April '96	Team workshop: «Satisfactions and insatisfactions in our work»	16 staff and trainees	3 h.
Sept '96	XIth Annual Congress on palliative care	5 staff and volunteers	2 days
Sept '96	Conference: «Aids and drug addiction» Regional Conference on Health	4 staff	3 h.
Sept '96	Conference on viral load	2 staff	3 h.
Oct '96	Staff review: «Team work» Centre Option Ouverte Jean-Marie Berlinguette	19 staff and trainees	2,5 h.
Oct '96	Information: «The health network and health reform» CLSC St-Henri Louis-Paul Thauvette	18 staff	1,5 h.

| Date | Themes and organizations | Participants | Time |

Nov '96	Conference: «neuro-aids and neuropsychiatry» Regional Conference on Health	20 staff	3 h.
Nov '96	Conference on community aids residences (study report) Roger Le Clerc	6 staff and volunteers	2 days
Dec. '96	Conference: «Role of workers and limits of intervention» Regional Conference on Health	3 staff	3 h.
Dec '96	Training: «Intervention and aggression» DMP St-Luc, Dr. P. Rochette	20 staff	2 h.
Jan '97	Training: «My own death Isabel Groulard, psychologist	7 staff	8 h.

Alternative approaches to health care

Alternative approaches to health care are an integral part of our work. For the past five and a half year, the committee for alternative approaches has been a consulting force for residents and staff alike.

These various approaches often complement traditional medicine. Through personal choice of theirs or because of the inefficiency of a particular medical treatment, residents often choose to explore alternative treatments.

Various approaches have been tested over the past years. Amongst these, several have had significant positive results and have since become an integral part of our care policies.

More and more often, members of our committee are called upon to share our experience in other resources, both in public institutions (clinics and hospitals) and at community level and groups of persons who simply express an interest in a global approach to health management and palliative care.

Here are a few examples:

Wounds

A mix of herb cream and Canadian *hydraste*. This mix has been used for pressure wounds and Kaposi wounds (on large surfaces of legs), in order to prevent discharge and infection. This same ointment has been used to successfully treat heel wounds, offering quick and effective relief.

Ingrown nails

Dipping of the infected area in water for twenty minutes, followed by an application of Canadian hydraste.

Also, we continue making use of **phytotherapy** products to alleviate flu symptoms as a sedative, or to fight urinary tract infections:

Flu

The flu has hit hard this year. Several residents and staff members have been sufferers. The use of *echinacea*, *infectix* (*echinea* dye and *propolis*), vitamin C and *ravensare* essential oil drops mixed with honey, have been successful in improving overall health of the sufferers and avoiding worsening of symptoms.

Nervousness and agitation

We use plants who are known for their soothing qualities, such as *calmis* dye (composed of oatmeal), *cataire*, *valerian* and *scutellaire*.

Urinary tract infections

Urinatea herbal mix: 1 liter a day, or «*urimix* melange»

In **phytotherapy** this year, we have been exploring several avenues to counter bursitis, knee pains and low body temperature.

Bursitis

For shoulder bursitis, pineapple juice, for use as a natural anti-inflammatory.

Knee pains

Ricin oil compresses, with application of a «magic bag» for one hour.

Low body temperature

One resident complained of being constantly cold. he began to absorb 1 *vareck* pill before each meal and after a very short time, his discomfort was gone and his body temperature rose again.

We have made use of **aroma therapy** more and more, in two particular instances in the last few years, namely cephalea and epilepsy, or convulsions.

Cephalea

Application of essential oils to the temples. Composition: *peppered mint* 2.5 ml, *bay leaves* 1.5 ml and *eucalyptus citriodora* 1 ml. After several unsuccessful treatments by analgesics against cephalea, one resident suffering from cerebral lymphoma expressed relief after an application of these essential oils.

Convulsions et epilepsy

A mix of aromatic honey consisting of *oregano, ravensare* and *romarin* essential oils.

This year, we have used **aroma therapy** to treat other problems as well, either internally or externally, such as neuro-muscular pain, herpes and candida:

Neuro-muscular pain

Massage using a mix of essential oils: *eucalyptus citriodora* 2 ml, *cananga odorita* 2 ml, *cypressus sempervirens* 1 ml, in 50 ml of canola oil. When pain is associated to circulatory problems, one may add *millepertuis*.

Herpes

For anal or oral herpes, a mix of essential oils: *melelenca alternifolia* 2ml, *melaleuca quinquinervia* 2ml, *calophylum inophylum* 5 ml, *menta spicata* 1 ml. If trouble persists: alternate essential oil mix in the morning and *calendula* cream at night.

Candida

Neutral lozenges on which are applied drops of essential oils: *melaleuca alternifilia* 20 drops, *melaleuca quinquinervia* 20 drops, *menta piperita* 10 drops, *eugenia caryophilus* 20 drops. One can add *hydraste* dye to gargle with.

All these experiments are part of an overall global approach that takes the whole person into account. The intervention on the physical level is always paired with care on the psychological level and often, on the spiritual level as well. The following story is an illustration of this:

Mobility

One resident, who was completely paralyzed on the right side of the body, was bedridden so that it was necessary to use a lift to move him. Following frequent shiatsu massages, with much listening care, he expressed feeling a return of circulation and tingling in his legs. He was doing some regular antigymnastic exercises using balls. Following this regimen, this person assumed his own mobility with the use of a wheelchair a few following weeks. For the past several months, he walks comfortably with a cane. Certainly, several unknown factors influenced this remarkable improvement, but undoubtedly, the approach used contributed greatly to motivate this resident to seek out and find again his physical autonomy.

On top of the abovementioned approaches, the personnel and volunteers of la Maison d'Hérelle who have appropriate training , regularly dispense sessions of massage, shiatsu, therapeutic touch, acupuncture, polarity, reflexology, reiki,

individual and group art therapy as well as services of naturotherapy and aroma therapy.

We are continuing this year, to fill the financial shortfall in our budget for alternative approaches to medicine, through the sale of honey jars.

In order to better evaluate the positive effects of these approaches, we will attempt in the coming year, to encourage residents who experience some benefits from these, to make use of them on a more regular basis and for more significant periods of time. Indeed, certain products have stronger therapeutic effects when they are used for a longer time and more diligently.

We wish to thank the following persons who have supported these initiatives:

Marie Provost, *herbal expert* and her team « La Clef des Champs »
Danièle Lacaille, *aromatherapist*
Maurice Nicole, *naturopath* et *aromatherapist*
Diane Therrien, *homeopath*
Richard Marcovitch, *naturopath*
Francis Pelletier, *naturopath*.

Special projects

There were two special projects carried out this year: participation in the community aids residences of Quebec study and the support of a new housing resource for children living with aids in Haïti.

1. The community aids residence study

Between the months of February and June 1996, a study was conducted by la Maison d'Hérelle of four (4) community aids residences, in order to establish the current level of loss of autonomy of the clientele. This study was ordered by the Consortium of Community Aids residences of Quebec (which brings together some twelve houses) and was included in the action-study by Mr. Roger Le Clerc on residences in Quebec.

Three houses in Montreal and one in Quebec City participated in this study, which included 36 residents.

The tools for this study included two forms, the *formulaire d'évaluation de l'autonomie* and the *formule de détermination des soins infirmiers et services d'assistance requis* du C.T.M.S.P. (classification par type en milieu de soins de services prolongés), which respectively are used to determine levels of autonomy in residents and levels of nursing care and assistance required. This method was used because it allowed on the one hand to meet the measuring criteria used by the Health and Social Services Network and, on the other hand, to determine the hour/care ratio of the services offered to the clientele.

Average for the four residences: 2 hours and 16 minutes per day per resident.

In community residences, the clientele is similar in terms of its loss of autonomy. According to the study, residents require between 25 minutes and 5 hours and 23 minutes of care a day. All of them experience loss of autonomy and the great majority of them experience terminal phase and die while in residence. The support relationship developed with the clientele constitutes an important part of the workers' job.

Despite the fact that these results result fairly accurately our daily experience, the role of the workers extends considerably beyond the care dispensed to residents. The additional tasks require a significant number of hours which the tools used in the study (CTMSP) did not allow us to measure (a list of these additional tasks is available in the report of the study). What the study suggests is that the clientele requires tremendous care and numerous services and that available financial resources[1] are less than adequate to ensure them.

In order to compensate, we rely, on one hand, on volunteers and on the good will of workers who very often work beyond remunerated hours, and on the other hand, on temporary staff who have access to subsidized employment. However, not only do these persons require training and supervision, cuts of up to 29% of the subsidies were announced this year. Certain programs were outright abolished in March this year.

Despite this, we are intent on preserving the community spirit in our residences because we are aware of its therapeutic weight and we wish to continue to have the opportunity to offer residents the highest standard of care.

The study is available on demand.

We wish to denote the participation of Mrs. Michèle Blanchard, Executive Director of La Maison d'Hérelle, in the advisory committee and the reading committee for the action-study of the Consortium of Community Aids Residences of Quebec, conducted by Mr. Roger Le Clerc.

2. <u>Project Haïti</u>

The project l'Arc-en-Ciel, in Haïti, began official operations December 1st 1996: the first foster care residence for impoverished Haitian orphans living with aids.

Located in Bouthilliers, near Port-au-Prince, the home can welcome 35 children. It is the work of Canadian-born Danielle Reid-Perette and her husband, Robert Perette who is originally from Haïti and who spent over fifteen years in Quebec.

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[1] Subsidies provided to the aids residences are equal to a per diem of $45.00 per resident, compared to actual costs (figures observed in 1996):
Short term care (min. 1.5 hours/care/day) = between $109 and $139a day
Long term care (min. 2.5 hours/care/day) = between $164 and $186 a day

Danielle spent several months with us at d'Hérelle in order to acquire some basic training on the care required by persons living with aids and on the operation of a residence.

This experience has enriched us with a special link to these people and this project: two of our workers have visited la Maison l'Arc-en-Ciel and we have set up a special committee in order to assist them in various ways.[2]

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2 Because of its responsibilities related to its role as a pilot project, la Maison d'Hérelle has allotted this project a supplementary budget.

4. The committees

Whether it be to better coordinate regular activities of the resource or to see to its responsibilities as a pilot project, certain persons are grouped into committees at la Maison d'Hérelle:

- Planning
- Admission of residents
- Evaluation and selection of personnel
- Support for family and friends
- Alternative approaches to health care

In preparation for Phase II, other committees have been created, some on a temporary basis in order to plan and organize specific projects, some on a permanent basis in order to respond to the needs of the lager clientele:

- Health care
- Volunteer training and supervision
- Construction
- Food services
- Maintenance
- Document review
- Rituals
- Finance

These committees are almost always composed of at least one representative of the groups affected by the services offered at d'Hérelle: staff, volunteers, residents and sometimes, a resource person from the outside. Below is an overview of the activities of each committee this year:

Committees created during Phase I

The planning committee

Created more than four years ago, this committee meets twice a month in order to establish priorities and determine the necessary steps for the proper operation and development of the resource. Strategies and decisions are discussed and later presented during staff meetings.

This committee assumes all the aspects of our mandate: resident care, volunteering, administration, coordination, training, tea support, representation in regards to other resources, participation in various events, etc.

It is in this forum that were discussed the most important decisions in preparation for Phase II.

The committee for admission of residents

This committee handles admission requests, manages the evaluation of requests through personal pre-admission interviews, maintains personal contact with persons waiting for admission or their referral service, etc. One member of this committee sits every two months on the Admission Committee of Aids Community Residences of Greater Montreal.

As housing capacity has increased, so too have admission requests since the onset of Phase II and the tasks of the committee are considerable.

The committee for evaluation and selection of personnel

A reorganization of remunerated personnel had to be achieved in order to fill new positions created in Phase II. A second night shift and more on-call positions were created, two regular full-time staff members who left the resource before Phase II had to be replaced and a half shift for maintenance was created.

The committee studied the selection process in light of the allotted budget for Phase II and reviewed the evaluation criteria in preparation for the larger clientele. This committee continues to ensure annual performance review of the personnel and the required support to maintain the quality of the work.

The committee for support of friends and family

In order to ensure continued support of friends and families, whose numbers have increased proportionately as the number of residents went from 11 to 17 in Phase II, this committee reviewed their needs and studied ways to manage human resources in accordance.

In fact, the action-study conducted on the aids community resources suggested this was an aspect requiring further development.

The alternative approaches to health care committee
The activities of this committee are described in Chapter 3 The pilot project mission.

Committees created in preparation of Phase II

The committee for care to residents
We have found it necessary to review the policies and contents of the training of volunteers in the form of pairing and supervision, because the increase in the number of residents require a different approach to the volunteer care.

The number of volunteer service hours have increased from four to five hours a week and at least two volunteers now support the worker.

Pairing between volunteer and worker has been replaced by small, 4 to 5 person teams of intervention, composed of one worker, two or more volunteers and a trainee.

The construction committee
In preparation for the renovation of the building of Phase II, this committee was mandated by the Board of Directors to administer the construction budget and to assume supervision of the development plans for Phase II, within the projected time-frame!

The committee met weekly for three months. Individual efforts to remain on budget, to actively seek out donors and to collaborate in the administration and management are greatly appreciated. The committee considers that the outcome of this intense activity is a true success.

The food services committee

Created to prepare for Phase II, this committee labored to reorganize this service in accordance with the increased volume in the house:

- Review of tasks for each shift
- Elaborate means to increase communication with other services
- Review volunteer roles as well as training and supervisory procedures
- Review menus and cost of meals
- Review the guide for care and hygiene in the kitchen
- etc.

The maintenance committee

This committee was also created to prepare for Phase II. Beginning with a review of needs for equipment and labour, the members have worked hard, namely on:

- Task descriptions of employees and volunteers responsible for maintenance
- Coordinating regular maintenance and minor repairs
- Reviewing procedures for washing, cleaning and disinfecting of areas as well as recuperation and processing of biomedical waste
- Updating the list of suppliers and the procedures for purchasing material
- And, of course, coordinating the clean-up of the new quarters prior to the start of Phase II.

The document review committee

Since Phase II marks the beginning of an important new step in the history of la Maison d'Hérelle, a small committee was created to review and update all documentation produced since 1990, from information pamphlets to residents' files to all the forms required for the operation of the resource.

The Rituals committee

In the new quarters of Phase II, two rooms have been put aside for what we have dubbed our personal and collective «rituals». They serve namely, for purposes of meditation, relaxation, massage and our own mourning rituals experienced as a group. We have taken the opportunity offered to us by the transition period to reflect on the importance of these activities for the staff, the volunteers, the residents and their loved ones. We benefited from the precious collaboration of Lisa Nantel, an artist, who developed an environment concept for what we consider «plains of passage». This experience has allowed us to appreciate the profound symbolic significance of the rituals that occur at la Maison d'Hérelle.

The finance committee

This committee is composed of members of the Board of Directors, the staff and members of the community. Created in the Spring of 1996, the committee pursues its objectives of planning and organizing fund raising for the following sectors:

1. Finance to acquire the Phase II building
2. Finance of Phase II (construction, renovation)
3. Finance overall operations

In the future, the committee will pursue activities for sectors 1 and 3.

5. Collaboration with other resources

Following is a list of organizations with whom we share daily activities:

- St-Louis-du-Parc CLSC, for the regular presence of Dr. Louise Lessard who was replaced this year by Dr. Blusanovics, who we welcome among us.
- CLSC Le Plateau who support us always with nursing care.
- The Centre Pierre-Hénault for its volunteer commuting services.
- The ACCM and la Maison Plein Cœur for its support and assistance.
- The Fondation d'Aide directe-Sida-Montréal for its financial assistance.
- The CPAVIH and the COCQ-sida for its assistance with a medication fund.
- The CLSC Centre-Sud and the assistance of Louise Pilon, psychologist.
- The DMP St-Luc, for its support and contribution to the team work.
- The COCQ-sida for its continued for recognition of community residences.
- The social workers who forward admission requests.
- The aids community resources of Quebec
- La Maison Magnus Poirier ;
- The La Clef des Champs boutique for their support in alternative approaches to health care.
- The Caisse Populaire St-Louis-de-France, for their personalized services and the availability of their locales.
- The Paroisse St-Louis-de-France ;

- Florist Fleurs Gilbert ;

- Restaurant La Tête de Violon, our second headquarters for meetings around café au lait and for the publicity for honey jars.

- The nuns of la Communauté Religieuse des Soeurs de la Providence for having welcomed us between August 15th and December 5th 1996.

Exchange opportunities remain essential, particularly in light of the health reform:

The Table des Maisons d'Hébergement Communautaire - sida du Québec

Some groundbreaking work was accomplished this year by the action-study on residences in Quebec. Our participation in the reading committee allow for continued reflection during the course of the project. Financed through Health Canada, this project has for objective the transmission and promotion of the Quebec model throughout the country. The publication of the book is planned for the Spring of 1997. This study will constitute a basic tool for our self evaluation process as well as a promotional tool for all the residences.

We wish to underscore the excellent work of M. Roger Le Clerc and the support from the reading committee: Mrs. Helen Gagné, M. Bernard Gendron and Mrs. Janet Dunbrack, representing the financial backers.

The COCQ-sida (Coalition des Organismes Communautaires - sida du Québec)

We are present on the executive committee of the Board of Directors and this has enabled us to be well-informed on the controversial dossiers the coalition champions: medical insurance, new treatments, prevention, education, aids in the work force, provincial and federal strategies and initiatives.

The Régie Régionale de la Santé et des Services sociaux

We played an active role in the elaboration of the Project on Palliative Care.

Our mandate as a pilot project continues, more and more powerfully and assumes many shapes and forms, namely, support for groups intending to open residences, in

other cities, in other provinces and in other countries. This entails training sessions and workshops that share expertise and experience, and technical support in regards to administrative management of care, personnel and volunteering.

6. Finance

Operations revenues

Support to community resources	378 000 $	
Per diem for the additional 6 places	32 670 $	
Centraide: program for the volunteering	55 000 $	
Contribution of residents		55 938 $
Donations		15 610 $
Autofinancing activities (including « Ça Marche »)	10 937 $	
Various revenues	15 170 $	
Interest revenues	15 069 $	
Program PAIE		11 774 $
Total	**585 168 $**	

Independent projects

Alternative approaches to health care (Farha Foundation and autofinancing)	1 200 $
Residents' Fund	2 035 $
Total	**3 235 $**

Donations specific to Phase II

Mr. R. Gilbert (Jacques Starr estate)	60 000 $
Mr. G. Lauriault	15 000 $
The Farha Foundation	5 000 $
The J. E. Lévesque Foundation	5 000 $
M.G.I. Consultant (Martin Grenier)	1 650 $
Total	**86 650 $**

7. Perspectives for the future

We will have to consolidate the scope of operations and activities in the coming year:

- Adjust and modify the wok of our teams regarding various types of interventions toward the residents and their close ones.

- Provide support and means to the finance committee, which will have a pivotal role to play in fund raising.

- Setup a reflection committee to study the impact of current changes in the fight against aids: tri-therapy, drug using and alcoholism among the clientele, increase in the care service requests. This committee will report to the Board of Directors.

- Offer continued support to the Maison l'Arc-en-Ciel.

- Pursue our mandate as a pilot project through training and support to other resources: structure and training of volunteers, alternative care and approaches to health management, palliative care and resource management.

Members of the Board of Directors

Dr. Richard Morisset	President Representing the university and medical communities
Daniel Brisset	Vice-president Representing the business community
Me Bruno Grenier	Vice-president Legal counsel
Jacques Briand	Treasurer Representing the hospital network
Bill Nash	Administrator Representing the business community
Louise Fortin	Administrator Aids and drug addiction
Charlotte Lambert	Administrator Representing the volunteers
Jean Brien	Administrator Member - CLSC du Plateau
Jude Lejeune	Administrator Representing residents
Pierre Pelletier and Michel Richard	Administrators Representing the employees
Michèle Blanchard	Executive Director

Employees

These employees were present during the year spanning 1996-1997:

Michèle Blanchard	Executive Director
Richard Desjardins	Volunteering coordinator
Anne Véronneau	Administrative secretary
Françoise Moquin	Care coordinator (part time)
Monique Bourdages	Accountant (part time)
Mireille Falardeau	Clinical supervisor (part time)
Claudette Blouin	Coordinator - food services
Claire Lacombe	Cook (phase I)
Fernand Fraser	Cook
Silvana Hanna	Assistant cook (on call - phase I)
Stéphanie Lacroix	Assistant cook (on call)
Laure Olivier	Assistant cook (on call)
Richard Peters	Assistant cook (on call)
Myriam Van Male	Maintenance coordinator (part time)
Reynald Mercier	Maintenance assistant
Ann Comtois	Maintenance assistant (on call)
Huguette Philibert	Care worker (phase I)
Xavier -Pierre Côté	Care worker (phase I)
Pierre Pelletier	Care worker (on call - phase I)
Michel Richard	Care worker
Judith Dendy	Care worker
Jean-Marc Meilleur	Care worker
Roxanne Landry	Care worker
Cindy Raess	Care worker
Roger Gagné	Care worker (part time)
Bernadette Bulcourt	Care worker (part time)
Marie-Lise Consigny	Care worker (on call - phase I)
Denyse Lavigueur	Care worker (on call)
Carole Durand	Care worker (on call)
Lise Germain	Care worker (part time - volunteer)
Claudette Isabelle	Care worker and assistant cook (on call)
René-Robert Vautrin	Care worker (on call)

Trainees

Subsidized employment

Martine Lemay	Intervention
Sylvie Gendron	Reception, than intervention
Michel Lussier	Intervention
Marc Michaud	Intervention
Madeleine Royer	Reception
Suzie Gagnon	Reception
Francyne Langlois	Reception

Students

Denis Dorval	Nursing
Marie-Josée Morin	Nursing
Rocio Ramirez	Nursing
Gina Castor	Nursing
Jennifer Harrison	Aids course
Rala Ajakie	Aids course
Annie Côté	Care worker
Marie Carmelle	Care worker
Amilie de Koninck	Specialized education
Leena Sarkar	Social work
Armelle Ratat	Psychology (France)
Philip Tristram	Psychosociology of communication