La Corporation Félix Hubert d'Hérelle

Rapport annuel d'activité
1998-1999

Table of contents

Word from a resident

Adjusting, full-time

My arrival at la Maison d'Hérelle was not painless. A full year of reflection had passed before I resolved to take the big step. So many decisions, so little time and I had to make the transfer during the course of my convalescence! Should I keep my apartment or not? How do I deal with all my belongings? Which do I keep, which do I store, which do I bring with me? Which do I discard forever? Forever?? Are you sure? Many questions often remaining unanswered!

Certainly, my decision to move in here was made. After numerous health problems and hospitalizations, my need for it was obvious. My introduction to la Maison went very well, so well that I wondered why I hadn't made the move until now. The welcome I received (as much from the staff as from the residents) was wonderful, but far from me to remember all those names! It was very odd at first to live with people experiencing similar health problems as me. I was unused to speaking with people living with the same concerns. Well, in any case! I hardly need to explain to each and everyone what I feel. They understand me!

Life here, at la Maison d'Hérelle, is not always easy. With the task of fighting this notorious virus which links us all, we must, all of us - resident, care workers and volunteers alike - deal with all that accompanies it. In regards to the physical environment as well as the social and psychological aspects... One must quickly learn to live as a community and set aside many of the old habits developed while living by oneself. We have to learn to deal as well with the health problems of others. It is far from easy to see someone become ill, be hospitalized and in some cases, lose their life. Our own precarious health, the fear of dying and the vision of our own descent into the loss of autonomy all renders us very vulnerable in these unhappy moments.

We mustn't forget the necessity to deal with an increasingly less homogenous clientele. Here, one finds all sexual orientations, various social classes, various age groups and many different types of health concerns. I was not at all prepared to deal with these many combinations! A lot of time and energy and patience and empathy was required to lower certain barriers and shed some prejudices towards others. And with all this, I almost neglected to mention the necessity to deal with the personalities of everyone and the drastic but essential measures the Maison d'Hérelle has to sometimes apply, in order to resolve some of the ensuing serious problems. Add to this the more and more frequent departures of some residents on the road to autonomy, which opens the door to some new people, which in turn forces yet another adjustment to our community life! Pfiew! This is full-time work!

What was particularly wonderful for me was to discover a new love amongst the residents of la Maison. The thought of a new love in my life was far in my mind. In a sense, I had resigned myself to the idea. In fact, how do we love? How must we share our lives? Have I ever known the answers? I don't remember! It has been so long! Lets let this ship follow its course. We shall see where it will lead!

And my health damnit! What about my health? How am I faring at d'Hérelle? Am I neglecting the Me?? Please! Set me straight!

Ghislain Bélanger

Word from a care-worker

You are much greater than you think

For six years already I have been a care worker at la Maison d'Hérelle and I still find it difficult to speak frankly about my work. For one thing because its very nature is constantly changing and evolving with the transformations characteristic to the symptoms and treatments of aids, but mostly because it is always challenging to explain things we do primarily with the heart, as opposed to the head and hands…

Working at la Maison d'Hérelle is indeed, for me, first and foremost a question of the heart. It is the choice of a work environment where each encounter is an opportunity to reach ever farther into the trust and the underlying strengths of others. Strengths and weaknesses…and every other facet which make up a human being at a certain moment in the course of their life; all the things we love in others, and all the things we love a little less.

And to love, I profoundly believe, is by no means to do everything and anything for someone else. Rather, it is to make yourself available, without taking up all the space, to be there without always being present, to help without necessarily solving everything. It is understanding and accepting one's limits as well as those of the other, it is indeed to leave him or her the right to choose his path, with the freedom that we all enjoy.

It means being rough sometimes…and even rougher with those we care so much about, more so than with those with whom we are indifferent!

It is to look upon ourselves and the other in the same manner. Lucidly and tenderly. Demanding and confident. That very gaze that says, with all the humility in the world: «You are much greater than you think».

Denyse Lavigueur

Word from the Executive director

Where there is Life, nothing is certain

This page, which is offered to me at the onset of an annual report, always makes me somewhat nervous as I must surmise in a few words the highlights of an entire year of life! Then again, I enjoy challenges of the sort!

First then, the good news! Five people have passed away this year, compared to eighteen last year! It is an extraordinary step toward a long awaited greater life expectancy.

The welcoming of residents is now done, in almost every case, on a «transitory» basis, since the onset of new therapies combined with the impact of the environment of la Maison, we are witnessing an important improvement in their health even in advanced cases. This new reality has ushered a time of experimentation for many attempting a «return home».

The sadder news is that HIV affects a greater number of people experiencing various other difficulties such as: mental health problems, homelessness, drug addiction and sometimes, a criminal record. These new problems, while driving us to confront our fears and our prejudices, has forced us to define more clearly the mission of la Maison… and the limits of the support that can be expected from the community.

These emerging needs surrounding the HIV-aids have transformed our old ways and practices. They have solicited many moments of reflection and second-guessing within the team, amongst the volunteers, the members of the Board of directors and the provincial Table.

It seems clear to me however that the question of community residences reaches far beyond the single most question of HIV. It is a societal question which encompasses such realities such as poverty, the lack of decent housing, immigration and isolation, hence the necessity for concertation: a sizeable challenge which we tackle on a day to day basis.

To add to the sadder news, the subsidies and donations destined to the fight against aids are less and less accessible… a consequence of which is our collective effort to streamline our fundraising strategies, and for myself personally, to become a new subscriber to business and commerce publishings!
I can only close after expressing again my admiration for those who fight for their lives, and offer my thanks to my colleagues, the volunteers and the members of the Board of directors who all believe in what we can achieve together and who support me so.

It is said that life is more powerful than death but that love is mightier than life… I profoundly believe this, as I have the privilege to dwell amongst people who put these words into action.

Thank you and pleasant reading.

Michèle Blanchard

1. Profile of the Clientele

Admission Criteria

May be admitted at la Maison d'Hérelle any person living with HIV-aids, who is experiencing loss of physical or psychological autonomy, requiring housing and support and this, without any form of discrimination. The principal affliction must however be directly related to HIV-aids.

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;
- A willingness to respect rules of participation and community living.

The following pages contain:

- An overview of the evolution of the clientele;
- A table presenting statistical figures reflecting the last two years of operations (1998 – 1999 and 1997 – 1998) and cumulative data from opening (1990 – 1999);
- 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 1999, warrant a number of observations.

Number of residents

Since the opening day of la Maison d'Hérelle, in May 1990, we have welcomed 211 residents. This past year, 35 people resided at la Maison, 5 of whom were admitted twice. Of these 40 admissions, 26 occurred this year. The additional 14 occurred prior to the 1st of April 1998.

Since December 5th 1996, la Maison d'Hérelle is capable of welcoming 17 residents: 16 beds are allotted to people requiring transitory or palliative care and 1 bed is reserved for people requiring short-term care.

Age upon admission

For the past 9 years, the average age has remained relatively stable, around 40 years. The majority (62% are between 30 and 45 years old.

Genders

Since it opened, la Maison d'Hérelle has welcomed a large majority of males, nearly 90% in nine years. This year, 23% of our clientele was female. This figure thus increases the overall average of our female clientele.

Sexual orientation

Between 1990 and 1997, less than 12% our clientele was heterosexual and this figure remained relatively constant during these first 7 years.

Last year, this category comprised 32% of the clientele and this year, 54%. For the first time in 9 years, the number of persons of heterosexual orientation is greater than those of homosexual orientation. These new characteristics reflect one of the considerable changes in the clientele.

Type of care

Last year, 24 residents out of 46, more than 52%, were undergoing an antiretroviral therapy on an on-going basis. This year, this number has augmented to 77%, or 27 residents out of 35. This new situation has had a direct impact on the needs of the clientele. Already last year, we were able to foresee a major change in the type of services required. This year has witnessed evidence of this change and we have had to redefine our programs and the related services. The second chapter *entitled New reality...new responses* (see page 30) outlines our principal adjustments.

The residents on transitory stay are increasing:

- 0 between 1992 and 1997
- 5 last year
- 11 this year

On the other hand, 5 persons admitted for palliative care this year and last year, have finally returned home.

Reasons for departure

Two notable facts emerge:

- 77% of residents returned to live at home, where the average for the previous years was 24%;

- There were only 4 deaths, or 15% of the residents, in comparison to 63% during the course of the previous years.

This situation brings into light the radical change in our clientele.

Length of stay

The average length of stay has been 7.5 months. This average is higher than the overall average of the first 8 years. An exceptional situation explains this discrepancy: one resident left la Maison d'Hérelle after the longest stay since the opening of the resource, 4 years and 8 months. After a lengthy convalescence (with no antiretroviral therapy), the health of this resident stabilized and he was able to return home.

Rate of occupancy

Palliative care and transition

Number of days occupied	5 127
Total capacity (1bed X365 days)	5 840
Percentage of occupation:	**88%**

Short-term care

number of days of occupation	241
total capacity (1bed X365 days)	365
percentage of occupation:	**66%**

Associated disorders

The following changes were observed:

Minor increases

Zona
Behavioural disorders
Hepatitis

Major increases

Encephalopathy
Candidoses
Drug addictions (last two years)

The increase in drug addictions amidst the clientele in the last two years is yet another determining factor observed amongst our clientele: 50% of our residents are affected. It should be noted that

it is often difficult to determine whether certain symptoms are related to neurological disorders or mental health problems.

Here are the highlights of the characteristics of the new clientele of la Maison d'Hérelle. Chapter 2 *New reality…new Responses* (on page 30) describes how we have responded to these changes:

- Increase in the female clientele
- Major increase in the heterosexual clientele
- Transitory care as the principal type of care and an increasing number of residents returning to live at home (organization of new services of reintegration and post-departure follow-ups);
- Radical reduction in the number of deaths;
- Significant increase in the clientele suffering from drug addiction (in the past two years).

Mireille Falardeau

Profile of the residents

Age

Genders

Note: Amongst the men, one person had a female identity, in the process of transsexualisation.

Declared sexual orientation

Family life

	1998-1999	%	1997-1998	%	1990-1999	%
No children	15	57,7%	24	77,4%	166	78,7%
With children	11	42,3%	7	22,6%	45	21,3%
Total	**26**		**31**		**211**	

Nationality

	1998-1999	%	1997-1998	%	1990-1999	%
Canadian	22	84,6%	25	80,6%	188	89,1%
Haitian	1	3,8%	2	6,5%	10	4,7%
Others	3	11,5%	4	12,9%	13	6,2%
Total	**26**		**31**		**211**	

Note : Others: (1990 to 1999): Chilean(3); French(2); Greek(2); Nicaraguan(1); Romanian(1); German(1); Portuguese(1); East Indian(1); Cuban (1).

Mother tongues

	1998-1999	%	1997-1998	%	1990-1999	%
French	22	84,6%	20	64,5%	162	76,8%
English	0	0,0%	6	19,4%	28	13,3%
Creole	1	3,8%	2	6,5%	10	4,7%
Spanish	2	7,7%	0	0,0%	5	2,4%
Others	1	3,8%	3	9,7%	6	2,8%
Total	**26**		**31**		**211**	

Note : Other (1990 to 1999): Greek (2); Romanian(1); German(1); Portuguese(1); Punjabi (1).

Financial resources

	1998-1999	%	1997-1998	%	1990-1999	%
Social security	17	65,4%	17	58,6%	125	59,2%
Salary insurance	2	7,7%	2	6,9%	37	17,5%
Quebec pension plan	3	11,5%	4	13,8%	22	10,4%
Unemployment insurance	1	3,8%	1	3,4%	8	3,8%
Workers' compensation	0	0,0%	0	0,0%	1	0,5%
RRSPs	0	0,0%	0	0,0%	1	0,5%
None	3	11,5%	1	3,4%	7	3,3%
Unknown	0	0,0%	4	13,8%	10	4,7%
Total	**26**		**29**		**211**	

Type of care

	1998-1999	%	1997-1998	%	1990-1999	%
Paliative care	7	26,9%	16	51,6%	125	59,2%
Transition	11	42,3%	5	16,1%	25	11,8%
Short-term	8	30,8%	10	32,3%	61	28,9%
Total	**26**		**31**		**211**	

Hospitalization(s) during period of residence

(from this point on, values reflect the number of residents having terminated their stay)

	1998-1999	%	1997-1998	%	1990-1999	%
None	17	65,4%	28	84,8%	140	70,0%
One	7	26,9%	1	3,0%	40	20,0%
Two	2	7,7%	2	6,1%	16	8,0%
Three	0	0,0%	2	6,1%	3	1,5%
Four or more	0	0,0%	0	0,0%	1	0,5%
Total	**26**		**33**		**200**	

Reasons for departure

	1998-1999	%	1997-1998	%	1990-1999	%
Death	4	15,4%	18	54,5%	113	56,5%
Returned home	20	76,9%	13	39,4%	61	30,5%
Other resource	2	7,7%	2	6,1%	17	8,5%
Hospitalization	0	0,0%	0	0,0%	7	3,5%
No reason given	0	0,0%	0	0,0%	2	1,0%
Total	**26**		**33**		**200**	

Length of stay

	1998-1999	%	1997-1998	%	1990-1999	%
Fewer than 3 months	8	30,8%	11	33,3%	73	36,5%
One to three months	2	7,7%	9	27,3%	40	20,0%
Three to six months	6	23,1%	7	21,2%	44	22,0%
Six months to a year	6	23,1%	5	15,2%	25	12,5%
Over one year	2	7,7%	1	3,0%	13	6,5%
Over two years	2	7,7%	0	0,0%	5	2,5%
Total	**26**		**33**		**200**	
Average (in months)	**7,50**		**3,30**		**4,80**	

Average length of care, by program

Paliative care	12,5 months
Transition	7,6 months
Short term	25 days

Place of death

	1998-1999	%	1997-1998	%	1990-1999	%
Maison d'Hérelle	3	75,0%	18	100 %	100	88,5%
Hospital	1	25,0%	0	0%	13	11,5%
Total	4		18		113	
Average age when died	45		42,7		40,6	

Associated afflictions

	1998-1999		1997-1998		1996-1997	
Total number of residents	35	%	46	%	34	%
Candidose	20	57,1%	20	43,5%	8	23,5%
Cryptococcosis	1	2,9%	1	2,2%	0	0,0%
Cytomegalovirus (C.M.V.)	4	11,4%	8	17,4%	6	17,6%
Dementia (cognitive)	1	2,9%	3	6,5%	2	5,9%
Depression	7	20,0 %	13	28,3%	6	17,6%
Encephalopathy/leucoencephalopathy	16	45,7%	12	26,1%	11	32,4%
Hepatitis	8	22,9 %	10	21,7%	9	26,5%
Herpes	4	11,4%	6	13,0%	15	44,1%
Recuring bacterial infections	2	5,7%	1	2,2%	3	8,8%
Lymphoma	0	0,0%	4	8,7%	5	14,7%
Mycobacteriosis (M.A.I. / M.A.C.)	3	8,6%	3	6,5%	5	14,7%
Paralysis	1	2,9%	3	6,5%	2	5,9%
P. carinii pneumonia	12	34,3%	16	34,8%	12	35,3%
Bacterial pneumonia	3	8,6%	3	6,5%	0	0,0%
Kaposi sarcoma	5	14,3%	8	17,4%	8	23,5%
HIV emaciation syndrome	3	8,6%	6	13,0%	5	14,7%
Drug addiction	16	45,7%	23	50,0 %	13	38,2%
Toxoplasmosis	5	14,3%	7	15,2%	4	11,8%
Behavioral troubles	4	11,4%	5	10,9%	2	5,9%
mental health troubles	5	14,3%	10	21,7%	13	38,2%
Pulmonary tuberclosis	0	0,0%	1	2,2%	2	5,9%
Zona	7	20,0 %	6	13,0%	5	14,7%

Note : Other (1998 - 1999): Cancer of the uterine wall(1)

The associated afflictions reflect the annual clientele; figures were taken from doctors' notes in the files of residents who stayed at la Maison d'Hérelle during the course of the year.

Admission requests at la Maison d'Hérelle

Admissions	26	46,4%
Admissions on waiting list	7	12,5%
Deceased before admission	1	1,8%
Admissions - from other resources	12	21,4%
Withdrawn admission requests	6	10,7%
Refused admission	4	7,1%
Total	**56**	

Note: Approximately fifty additional requests were presented informally at la Maison d'Hérelle (requests for information regarding services, admission criteria, etc.)

Support for friends and family

service	persons	hours
Psychological support	69	213
Information regarding progression of the illness	68	89
Social economic support	19	54
Counselling regarding care	18	28
Legal and para-legal counsel	17	27
Alternative approaches to health management	7	8
Meetings with the physician	6	4
Spiritual and grievance support	3	5

Other services offered:

8 meetings with family members, friends, and cultural community groups were held this year, in response to either a need for information regarding the state of a resident's health, for psychological support, to dispense information regarding the services offered at la Maison, for a funeral ceremony or to assist in the organisation of support services for residents returning home. 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.

2. New reality…new responses

Some thoughts from within

Miracles… to organize

You could describe this year as a cornerstone year at la Maison d'Hérelle. Everyone is aware that the availability of new therapies has transformed the fight against aids, But what people are far less aware of is the reorganization that was required at la Maison d'Hérelle, in order to assume this new direction. Of course, there is still a lot to do, but this past year marks something of a new beginning.

A new beginning that occurs within a deep historical continuity as well as within an inevitable rupture with the past: la Maison has always maintained its role as a place of accompaniment for people living with HIV and there lies the continuity of the project that is la Maison. The rupture comes from the fact that death is no longer the inevitable exit, but rather that the options point to a life that needs to be rekindled.

At la Maison d'Hérelle, the process of exploring and constructing an intervention method that deals with a person suffering through the problems and difficulties which he or she encounters, is far from over. To accompany is to bridge the relationship that will grant the recognition that the other deserves. The task is far from easy as very often these bridges have been the source of shame and hurt, were devalued and underestimated. In a sense we have to rebuild a social link that was responsible for shredding the self-image. In that context, to accompany means to firstly grant recognition to the sufferer in order to allow him to reclaim his place in a society which has not always valued him. The results are not always good, as the scars are often deep and our own failings, fears and pettiness are

numerous. Nonetheless, the desire to learn and to transform oneself is there.

Thus continues the «palliative care» at la Maison d'Hérelle. Indeed, palliative care is now the ability to be there and be available rather than a to-do and to-know situation. Much more than an intervention technique that is often inefficient when it is not supported with symbolic and interrelational work, palliative care consist first and foremost of mannerism and state of mind. It is this state that endeavours to adjust to the residents who are greatly changed.

To succeed though, this state requires means, tools and practical outlooks that will give it shape. And it is at this level that the team work and the planning was more sharply felt this year. While the planning committee set out to reach its objective of supporting intervention, the whole team was brought to reflect and discuss, on a regular basis during the course of its meetings, the proposals of the committee.

Thus the programs of la Maison were redefined in order to sharpen the objectives of the intervention. With this, la Maison opted to also pair off each resident with a primary and a secondary care worker. The primary care worker is in charge of the accompaniment strategy while the secondary care worker is there to support and substitute if need be. Each care worker ensures the regular follow-up with the residents under his care and provides a regular report to the team with his expectations. In order to ensure better knowledge of the situation of each resident and adequate care, la Maison devised a billboard where are the broad lines of the elements likely to favour a better intervention and a more concise evaluation, are outlined.

This renewal of la Maison is guided by concerns for increased rigour but tempered by flexibility, which is so essential to intervention. These concerns have not been without consequence in the accompaniment strategies which went through some profound changes. Finally, with the transformation of aids, we had to devise a

follow-up plan for the post-departure cases coming out of the transition program. There again, the task was great and the discussions were abundant. In the end, the team is beginning to get a better handle on its expertise.

All that has been said is far too succinct to adequately surmise a year abounding of hard work, of deep thought, or reorganization, of tensions… And there remains, and will always remain, much to do to become what we strive to become.

Gilbert Renaud

Our changing role

Following the considerable changes in the clientele of the community aids-residences, we have revised the programs offered to our residents.

Updated definitions of the programs

Palliative care: for terminally ill residents, those in pre-terminal phase or those who will not be healthy enough in the foreseeable future to regain their autonomy and return home. Some people have suffered irreparable damage, in particular on the neurological level, and returning home is almost impossible to envisage presently. These people require daily care, for a more or less prolonged duration.

Transitory care: for convalescing people who come to la Maison d'Hérelle to recuperate and eventually regain sufficient autonomy to return home. These people require re-integration support and post departure support as many of them, for a long period of time, have been extremely dependant of external resources institutional, community based) or from the environment (spouse or partner, family, friend) in order to survive. We offer transitory residents a three to nine month stay, according to need, with periodical evaluations.

Short-term care (dépannage): for people requiring short-term care, in a crisis situation or in order to offer some respite to their support system that is either exhausted or temporarily unavailable.

The reintegration of residents and the post-departure follow-ups

The accompaniment strategies which, until now, consisted primarily in reducing the undesirable effects of the illness on various levels (physical, psychological, social, economic, emotional, etc.) have been transformed dramatically.

We had got into the habit, out of necessity, to formulate some objectives that supported our intervention toward persons who were dying. But when the situation reverses itself and the health of the residents justifies less and less the type of support offered in residence, we then begin the process of reintegration.

For people preparing themselves for death, time and again, suffering one loss after another, the prospect of a new lease on life is often received with more anxiety than enthusiasm. These persons have left their jobs, their homes, their belongings, they have seen their closest friends and their partners die, they have often been taken up by either their close ones, one of the health network organizations or a community resource... and now, they must start over, reclaim their lives on all levels!...But for how long?

«...the experience of returning to life could be felt as a second shock.»*

The accompaniment strategy for a person under transitory care should take into account several factors:

- Physical autonomy;
- Capacity to accomplish life's daily tasks;
- Psychological state;
- Available resources to survive at home;
- Availability of close ones;
- Financial independence;
- Post departure needs;

* Translated from C. BOULOS, C. BOURQUE, P. VEILLEUX, Survih, Répercussions psychologiques des nouveaux traitements contre le VIH, Frontières, Automne 1998 – hiver 1999, p.51 –54.

- etc.

The services offered by the team pursue the objectives identified by the resident himself with the help of the principal (or secondary) care-worker, at his pace.

Services offered in the transition program:

Nearly 300 hours were logged this year in new services that were unavailable until now in the aids community residences. These services included, namely:

- identification of the needs surrounding the return home;
- psychological support, particularly in light of the anxiety and uncertainty related to the reintegration into the community;
- assistance in the search for financial assistance;
- support with daily tasks;
- support in gradual autonomy regarding the absorption of medication;

Services offered in the transition program (continued):

- assistance in the search for a dwelling and some furniture;
- assistance in the administration of personal finances;
- search for home care;
- organization of support systems;
- search for legal aid and assistance;
- assistance in meal planning;
- etc.

A start-up kit was devised by the kitchen team, containing some basic food products (of an approximate value of $25). This kit is offered at no cost to the residents who need some help to better organize their departure from la Maison d'Hérelle. Some simple recipes and some practical advice on food products (such as cost and nutritious value) as lightened the task for many.

Services offered regarding post departure follow-ups:

More than 200 hours were logged helping residents after they had left, thanks to a grant from the COCQ-sida in the scope of the «Return Home» project. These services included, namely:

- house calls;
- assistance with daily tasks;
- evaluation of needs and available services for home care;
- psychological support;
- evaluation of autonomy regarding the absorption of medication as well as the maintenance of personal finances;
- conflict resolution (occasionally);

Furthermore, over 100 meals were served at la Maison d'Hérelle to a dozen ex-residents.

The adjustment reaches other aspects of the team's role:

Firstly, a new relationship has emerged with the medical community: a common effort of support in regards to the residents has become necessary to the recovery of their health. The observations noted in the medical files of the residents have proved to be important qualifiers to improve the control of the protocols regulating the new combinations of antiretroviral therapies. The increases in medical appointments and hospitalizations for crisis interventions, require from us some more rigorous follow-ups. This year, for instance, nearly 50 visits to some 12 residents who were hospitalized for treatments for a more or less lengthy period, required from us almost 90 hours of intervention.

Furthermore, the ever closer collaboration with other professionals social workers, psychologists, etc.) is a significant factor in the

successful accompaniment of residents on their way to reintegrating the community.

Mireille Falardeau

3. Volunteering

Volunteering at la Maison d'Hérelle

The year that has passed represents a particular important step for volunteering at la Maison d'Hérelle because, despite the difficulties encountered, the inventiveness and devotion of our «old» volunteers and the generosity of those that have since joined us, allowed us to surpass the number of volunteer hours that was reached last year: 29 400 hours this year, 26 600 hours in 1997 – 1998.

The challenges we faced were two-fold:

First of all, the repercussions of the antiretroviral therapies and the new problems related to aids have brought on some important changes in the clientele, which in turn, solicits a different type of motivation from the volunteers. This explains, in part, the decrease in the number of persons who offered their services as volunteers this year: 100 in comparison to 160 the previous year. Fewer cases of palliative care and more cases involving mental health, homelessness, prostitution and drug addiction have required from the volunteers some extraordinary open-mindedness and an exceptional capacity to work in a field which often seems less engaging. Furthermore, the media have often projected the idea that the problem of aids is «solved», which gives the false impression that there are fewer needs than before in community work.

Secondly, in the last two years, we have noted that in many fields associated with volunteering, people are generally less available to commit to a volunteer activity on a regular basis, whether it is because they are themselves in a difficult personal situation or because of insecurities related to the current economic situation.

However, from these obstacles has emerged a new community movement which could be qualified as a new social conscientiousness, as much from community groups as from individuals, causing a new type of commitment. Thus we have seen this year some new people join the social project that is la Maison d'Hérelle. While Don Coggan was creating a Web site that suddenly gave us life on a global level with the opportunity to transmit our strategies, «Y» established an internal computer network which will be supported by the company he works for (both of whom who preferred to remain anonymous). Others, meanwhile, have formed a team which will support our fundraising activities. More and more, people spontaneously offer their support with some free gestures, such as lending us some equipment for a special activity or discreetly dropping by with some flowers to lighten our hearts. And then there are those who return every week, as they have done for years, who have had the opportunity to question themselves, to evaluate their priorities and who have reaffirmed their commitment to support us and to accept the new challenges.

Special mention must be made of the volunteer contributions of the paid staff. These people have contributed their efforts well beyond the «free over-time» which they have always offered. On top of which, due to the financial limits of la Maison, they must constantly add tremendous audacity in their creative initiatives. Amidst the numerous projects, three are worthy of a special mention. The creation of a book (for which the launching date is planned for the Fall of 1999), which consecrates, before it becomes a distant memory, the community approach developed in palliative care (through the common efforts of the residents themselves, the volunteers and the staff, who have all developed some remarkable skills), with the help of the care workers who shared their experience and understanding of the many end of life encounters they have had at la Maison d'Hérelle. The creation of the corporation Alternat by four care workers who formed an association to support la Maison financially, while promoting a fundamental aspect of care which is very dear to us: alternative health treatments. And, finally, the summer and winter

camps, at Jean-Marc's cottage, where residents experienced some intense and extremely precious moments. This project was realized with the generous collaboration of *The Children Of A Looser God*.

New means of accompaniment had to be developed to support the residents in the return to the community. This was an endeavour that was only possible with the collaboration of open-minded partners prepared to adjust the services normally offered in residence only: these new services are now offered, in part thanks to some trainee exchanges between community aids residences, a greater involvement of the social workers and the active participation of other organizations, such as la Fondation d'Aide directe sida Montréal. The benefits or these partnerships are already visible, as much amongst the aids network as other networks (such as mental health, drug addiction, etc).

The strategies developed by la Maison d'Hérelle, which strives to promote autonomy in the residents by encouraging their strengths rather than insisting on their incapacity and ineptitude, have been fruitful. This is how the residents, of their own accord, have begun involving themselves in the organization of la Maison: in decisions regarding the services, through their contribution to daily tasks as well as in the community, through their many conferences and talks.

Centraide has understood well the difficulties with which we are faced: the decrease in people volunteering, the ten-fold increase in the workload in response to the various new problems, the need for updated contents in basic training and continuous education as well as the importance of sharing and dispensing the expertise developed by the aids community organizations. I wish to point out the 30 000 $ increase in their grant, raising their financial support to 107 000 $.

In conclusion and in the hope of giving homage to the residents and their ability to teach us how to live, something to add to our cautious know-how, I would quote Andrée Pilon-Quiviger in «Au coin de la quarante-septième» (Leméac, 1983, page 179):

Had I not met you, I would not be quite the same. And I believe there is in this mutuality something resembling love.

Richard Desjardins

Statistics on volunteering

sector	persons	%	hours	%
administration	24	5,2%	2 926	9,9%
alternat	8	1,7%	3 128	10,6%
alternative approaches	15	3,2%	1 403	4,8%
others	295	63,6%	4 524	15,4%
Board of directors	11	2,4%	656	2,2%
consultants	4	0,9%	96	0,3%
kitchen	15	3,2%	1 664	5,7%
intervention	28	6,0%	3 039	10,3%
Personnel	33	7,1%	5 879	20,0%
Employment programs	4	0,9%	2 479	8,4%
residents	11	2,4%	459	1,6%
trainees (students)	16	3,4%	3 175	10,8%
total	464		29 428	

Sectors of involvement of the volunteers

- Administration : Board of Directors; co-ordination; recruiting.
- Assisting the workers: general support; hygiene care; etc.
- Vigil and attendance
- Alternative approaches to health management: massotherapy; reiki; shiatsu; therapeutic touch; phytotherapy; aromatherapy; musical

therapy; mental imagery; relaxation; meditation; visualization; art therapy; naturotherapy; homeopathy; chi kong; zootherapy; etc.

- Socio-cultural activities: planning and organizing, ticket sales, music, etc.
- Kitchen assistance
- Nutrition and healthy eating
- Fund raising
- Reception
- Accounting
- Software analysis and concept
- Painting
- Repairs and renovations
- The Journal
- Hair dressing and grooming
- Sewing
- Legal care: lawyers and notaries
- Attendance on committees and meetings
- Accompaniment in-house
- Accompaniment in the community (medical appointments)
- Accompaniment for follow-ups (post-departure)
- Accompaniment of close ones
- Voice choir
- Graphic drafting
- Publicity design
- Assistance to trainees
- Transmission and representation: training in other resources, representation before federal and provincial authorities, health care networks, community networks and partnerships
- Pairing
- Training

4. The pilot-project mission

Sharing the know-how

It is important to acknowledge the leadership role la Maison d'Hérelle as assumed in light of the rapid adjustments which we have accomplished.

Thanks to the good will of the team, the planning committee and the support of University of Montreal Social Work professor Gilbert Renaud, we have been proactive in forging some new work strategies. These affect namely:

- the admission criteria;
- the various types of care;
- the accompaniment programs;
- the reintegration and the follow-up of ex-residents.

The opportunity to write and share these work documents has enabled us to move ahead with discussions involving the provincial Table as well as other regional and provincial forums.

The contribution of Mr. Renaud is worthy of mention in this regard, as this has been an effort to bring together the practices of the community and the university. His presence at the team meetings, the planning committee , his contribution to the drafting of documents and of course, his discipline, have had a extremely important impact on the whole of the work accomplished.

In the context of community reintegration, care workers and co-operative program supervisors Cindy Raess and Judith Dendy have prepared a working paper on the intervention phases necessary for

this aspect of the lives of the residents and the care workers. We hope to consecrate these documents in the field and propose it to other resources in the near future.

The pilot-mission project that is such a large part of la Maison d'Hérelle's existence was pursued concretely, with amongst others, the construction of a Web site reflecting who we are and taking on the challenge of increasing our visibility, in an updated, continuous evolution, before the world! Thanks to the support of Don Coggan and the diligence of Anne Véronneau, this project has taken off. I invite you to take a virtual tour... www.herelle.qc.ca

The creation of a public relations committee has resulted in greater visibility in the media as well as some planning of fundraising activities. Though we have not yet been able to evaluate the impact of the article by La Presse's Philippe Cantin (reproduced in see in annex on page 61). The committee, consisting of Mireille Falardeau, Françoise Moquin, Pierrette Lanoix and Michel Levac has the mandate of seeing to it that this visibility is maintained and that special events are adequately publicised. One at a time, we are familarizing ourselves with terms such as «notoriety», «public image», «marketing», etc, not without our share of difficulties!

Michèle Blanchard

Alternative approaches to health management

Alternative approaches to health management consist of course, of an array of therapies such as phytotherapy, aromatherapy, naturopathy, homeopathy and massotherapy, but they consist mostly in a philosophy and basic intervention principles which put to use the

inward resources of the individual in the reconstruction of his or her vitality.

This year, we have witnessed important transformations in over a dozen residents who, admitted at la Maison with severe loss of autonomy and even, in about half the cases, in terminal or pre-terminal phase, were able to regain sufficient autonomy to undertake antiretroviral therapies. A few of them returned home during the course of the year.

It is the residents themselves who tell us that it is the attention, acceptance, faith and love which we communicate with the small daily gestures (massages, touch, relaxation, etc) which have helped them regain a taste for life and the feeling that they still possess control over their on lives.

Moreover, the natural therapies help many people tolerate the side effects of the antiretroviral therapies. Certain symptoms are better regulated: cephalias, nausea, abdominal pains, deficiencies of the pancreas and liver, cutaneous eruptions, etc.

Some energetic effects develop from alternative approaches. Many of these therapies lead to re-establishment of the balance between physical and emotional strengths of the person. We have observed these positive effects in people suffering from mental health troubles associated with aids: certain anxiety attacks, anger or deep sorrow crisis are soothed with the application of therapeutic touch, shiatsu or reiki massages, or even mixed tinctures which are known to reduce stress and intense emotions.

One story amongst many others

In order to illustrate our approach, here is the story of one resident of la Maison d'Hérelle. this resident, whom we shall call Sung in order to protect his privacy, was welcomed at la Maison with one month to

live. Bed ridden, catatonic, he was referred by the hospital after he had stopped being fed through intubing. Sung had come to la Maison d'Hérelle to die.

Though his needs were primarily considered through palliative care, the care workers nonetheless persisted in considering Sung as someone with a potential to regain his health. Leg massages, passive exercises, some warm comfort and mostly, our soft communication methods allowed Sung to progressively regain some unexpected autonomy.

Firstly, after only one week, Sung began to speak again, in his mother tongue. Of Asian origin, the language barrier with him was a difficult hurdle, but with much gesturing and by learning a few words in his tongue, we were able to acquire a better grasp and encourage his cultural habits, in particular his feeding and clothing habits. We then had some contacts with his cultural community which helped us to better understand Sung and his needs. We also made use of pictograms to communicate.

Several natural therapies contributed to a better quality of life for Sung: Vitamin B complex as a dietary supplement, camphor romarin oil massages in the liver region, as he was complaining of pains in this region and had a yellowish skin tone, homeopathy to relieve bleeding haemorrhoids.

After about six weeks, Sung regained some weight, his muscular capacity increased and he began a relearning process of his daily activities. It was about this time that Sung's physician established that Sung could gain access to an antiretroviral therapy. Some side effects appeared: an irritation of the scalp which was controlled with a mix of essential oils, and some stomach pains, alleviated with some herbal tea when he absorbed the medication.

Sung then began to participate in musical therapy sessions, guided meditation and artistic expression through drawing and clay

modelling. After six months with us, we have started planning Sung's return home, with daily support from his cultural community. We continue to encourage his increasing autonomy to this day, so that he may reach this objective.

We cannot ignore the human potential for recovery because we know that by rebuilding belief in abilities, in encouraging self-esteem, in granting and stressing the importance of the individual as a unique person, we are joining the resident in a healing of the heart, and often, of the body. We witness beings going through some profound transformations.

Mireille Falardeau, and the committee for alternative approaches to health management

Musical therapy

Last September began, at la Maison d'Hérelle, a musical therapy project who's objective was to increase the quality of life of the residents.

During my entire training, all the residents participated from near and far to this project and I had the particular privilege to follow, in individual sessions, two residents of la Maison. The two individualized accompaniment strategies gave me a chance to observe and record the incomparable benefits that music brought them both. Their interest in music as well as their personal belief in its benefits on their lives, favoured their full implication in the proposed activities and very often, supported their creativity.

The accompaniment strategy has the following objectives:

- alleviate pain;
- encourage outward expression of emotions;
- reduce emotional tensions and stress;
- increase concentration;
- rebuild self-esteem;
- encourage better communication with peers;
- increase quality of life;
- foster inward peace and serenity;
- aid in the search for a meaning to life.

During seven month training, the climate of trust which progressively took shape between myself and the residents supported the success of the project. The benefits of musical therapy were clearly obvious and very well received, on the individual level as well as in the general atmosphere of la Maison; in particular on Monday afternoons and on the occasion of birthdays or special events, during which time songs provided a sense of joy and pleasure of being together… just to sing.

I wish to specifically thank the management of la Maison d'Hérelle for their support and encouragement all along the course of this project and for the opportunity to complete this training.

Sylvia Sante

Trainees at la Maison d'Hérelle

Once again this year, several trainees of various fields were welcomed at la Maison d'Hérelle:

Student trainees

sector	Persons	hours
special education	7	1 968
inter-organizations (aids)	2	121
nursing care	2	88
psychoeducation	1	410
multimedia	1	294
family auxiliaries	1	140
technical nursing care	1	112
psychotherapy	1	42
total	**16**	**3 175**

Trainees in employment programs

sector	Persons	hours
intervention	3	1 839
reception and secretarial	1	640
total	**4**	**2 479**

Training offered and received by the staff of la Maison d'Hérelle

Training received

In order for the team to continue to offer quality services which correspond to the current needs of the clientele, several members participated in workshops, discussion groups or attended talks on subjects related closely to the problems associated with residences and the administration of a community resource.

Over 200 hours of training were logged by the staff of la Maison. Here are the principle themes:

- update on the medical status of aids;
- new combinations or retroviral therapies;
- alternative approaches to health care (homeopathy, polarities);
- drug addiction;
- homelessness;
- transsexualism;
- mental health;
- community reintegration;
- administration and publicity (non-profit organizations);
- internet and e-mail;
- etc.

Training offered

The expertise we have acquired over the years is shared, amongst others, in the form of conferences and theoretical and practical workshops. Approximately forty hours of training were conducted for the benefit of other resources. The recurrent themes for which we are solicited are the following:

- aids community residence care;
- alternative approaches to health management;
- personal assistance
- nursing care and HIV.

One must also take into account the training exchanged amongst ourselves, in accordance with our respective expertise, the debriefings from training received by a delegate of the team and, of course, the numerous hours of practical in-house training, in the scope of the work done with trainees and volunteers.

Mireille Falardeau

5. Collaboration with other resources

We wish to acknowledge the precious collaboration that we have received and continue to receive from the following organizations:

- St-Louis-du-Parc CLSC, for the regular presence of Dr. Blusanovics;
- CLSC du Plateau, for their care workers: nurses, social workers and physiotherapist;
- The University of Montreal Department of Social Work, for the support of Professor Gilbert Renaud;
- La Maison Plein Cœur, for their support, accompaniment and their van!;
- The Fondation d'Aide-directe-sida-Montréal, for their assistance in the community reintegration program;
- The St-Luc DMP, for their social care workers;
- The COCQ-sida, for their support and political representation, their input and the use of their locales;
- The aids community resources of Quebec;
- The Magnus Poirier House;
- The La Clef des Champs boutique for their support in alternative approaches to health care;
- The Caisse Populaire St-Louis-de-France;
- The St-Louis-de-France Parish;
- Daniel Bourget, of St-Joseph-du-Lac, for the honey;
- Isabelle Véronneau, graphic artist;
- The Dorothée Minville Pharmacy;
- Interjonction;
- L'UQAM, for the use of their locales during the summer;
- Mr. Gilles Duceppe, Member of Parliament for Laurier - Ste-Marie;
- The Communauté religieuse des Sœurs des Saints Cœurs de Jésus et de Marie, for the presence of Lise Germain.

Michèle Blanchard

6. Finance

Operation revenues

Provincial assistance to community resources	476 418 $
Régie Régionale : the Extra program	3 200 $
Centraide : volunteer program	77 132 $
Contribution of residents	86 156 $
Donations (see Principal donors)	92 340 $
Fundraising activities (see description)	22 815 $
Various revenues	12 537 $
Total	**770 598 $**

Independent projects

Alternative approaches to health care (fundraising)	3 300 $
Residents' Fund	1 349 $
Total	**4 649 $**

Principal donors

Mac Aids Fund (food aid)	58 450 $
The Louis Lévesque Foundation	10 000 $
Glaxo Wellcome (reintegration project)	5 000 $
The Jacques Star estate	3 100 $
Sœurs des Saints Cœurs de Jésus et de Marie	1 500 $
The Banque de Montréal employees Fund	1 000 $
The Brothers of the Franciscan Order	1 000 $
Normand Cusson	1 000 $
Various donations (less than 1 000,00 $)	11 290 $
Total	**92 340 $**

Fundraising activities

Les «24 heures» and the bowl-a-thon	10 000 $
Ça marche - Farha Foundation	8 600 $
Flea Market	1 000 $
Massage-a-thon	800 $
Other activities (less than 100,00 $)	2 415 $
Total	**22 815 $**

The search for funding

This new initiative has proven more and more necessary and urgent to respond to the needs of all the activities of la Maison.

We wish to thank the persons who have enlightened and particularly inspired the members of the team and those of the Board of directors, by their presence and their expertise at the heart of the fundraising committee:

Don Coggan;
Gustavo Argarez;
François de Beaulieu;
Michel Renaud;
Michel Levac.

We also wish to thank Philippe Dusseault and Anne-Marie Hétu of the *Match TV Néofilm* production «*Les enfants d'ailleurs 2*», for their generous contribution in clothing and equipment.
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Financial projections 1999-2000

Provincial assistance to community resources	476 000 $
Régie Régionale : the Extra program	5 000 $
Centraide : volunteer program	107 000 $
Contribution of residents	85 000 $
Donations	100 000 $
Fundraising activities	55 500 $
Various revenues	9 500 $
Total	**838 000 $**

7. Perspectives for the future

Here are the principal objectives which we have set for ourselves in 1999 – 2000 :

- In the context of the new emerging need of the clientele, continue to adjust our approach toward the residents who are in our care for a transitory period.;

- Develop the community reintegration aspect, with our partners in the aids network as well as other groups working in the fields of social housing, mental health and drug addiction;

- Remain present and involved with the political and financial leaders in regards to the foreseen transformations, which will affect the services offered to persons living with HIV-aids;

- Consolidate our operating and development budgets while insuring support to the individuals involved in the fundraising efforts;

- Continue our pilot project responsibilities through training and support to other resources and through the transmission of documentation.

Michèle Blanchard

Members of the Board of directors

Dr Richard Morisset	President Representing the medical and university communities
Bill Nash	Vice-president Representing the business community
Me Bruno Grenier	Vice-president Legal counsel
Jacques Briand	Secretary and Treasurer Social worker, representing the hospital network
Jean Brien	Administrator Representing the community
Pauline Desautels	Administrator
Raymond Veilleux	Administrator Representing the volunteers
Pierre Labbé Gary McCarrick	Administrators (each in turn) Representing the residents
Michel Richard	Administrator Representing the employees
Michèle Blanchard	Administrator Executive director of la Maison d'Hérelle

Employees

These employees were present during the year spanning 1998 - 1999:

Michèle Blanchard ..... Executive Director
Richard Desjardins..... Volunteering coordinator
Anne Véronneau..... Administrative assistant
Francyne Langlois ..... Administrative assistant and reception support
Marie France Daigle..... Administrative assistant and reception support
Monique Bourdages ..... Accounting services (part time)
Françoise Moquin..... Care coordinator (part time)
Mireille Falardeau..... Clinical supervisor (part time)
Claudette Blouin ..... Coordinator - food services
Fernand Fraser..... Cook
Claudette Isabelle ..... Assistant cook (on call)
Stéphanie Lacroix ..... Assistant cook (on call)
Laure Olivier..... Assistant cook (on call)
Sylvain Dolbec ..... Assistant cook (on call)
Myriam Van Male..... Maintenance coordinator (part time)
Reynald Mercier ..... Maintenance assistant
Alain Janelle ..... Maintenance assistant (on call)
Anthony Early..... Maintenance assistant (on call)
Michel Richard..... Care worker
Judith Dendy..... Care worker
Jean-Marc Meilleur..... Care worker
Roxanne Landry..... Care worker
Cindy Raess..... Care worker
Caroline Binaud..... Care worker
Denyse Lavigueur..... Care worker (part-time)
Carole Durand..... Care worker (part-time)
Daniel Levac..... Care worker (part-time)
Bernadette Bulcourt..... Care worker (part time)
René-Robert Vautrin ..... Care worker (on call)
Ann Comtois..... Care worker (on call)
Pierrette Lanoix..... Care worker (on call)
Elphège Léger..... Care worker (on call)
Nancy Leblanc..... Care worker (on call)
Dave Pettigrew..... Care worker (on call)
Ghislaine Roy ..... Care worker (on call)

Joffré Manelli ..... Care worker (on call)
Cathy Boulianne ..... Care worker (on call)
Duane Mansweld..... Care worker (on call)
Raymonde Paquette ..... Care worker (on call)
Denis Bourcier..... Care worker (on call)
Sonia Carval..... Care worker (on call)

Trainees

Employment program

Thounkéo Khammounheuang Care work
Marcel Bisson .....Care work and kitchen
Jacques Babeu.....Care work
Renée Lapatrie .....Reception et secretarial

Students

Élise Patenaude .....Specialized education
Isabelle Lévesque.....Specialized education
Joffré Maneli .....Specialized education
Johanne Gouskos.....Specialized education
Josée Desautels.....Specialized education
Karen Rousseau .....Specialized education
Mina Cotrocoïs .....Specialized education
Catherine Brassard-Meilleur Psychoeducation
Marie-Yva Justafort .....Nursing
Michel Regat .....Nursing (France)
Marie-France Lavallée .....Technical nursing care
Elphège Léger .....Family auxiliary
Christian Bergeron .....Multimedia
Céline Godbout .....Psychotherapy
Lyne Robichaud .....Inter-resource aids
Pierre Delage .....Inter-resource aids

Annexe

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