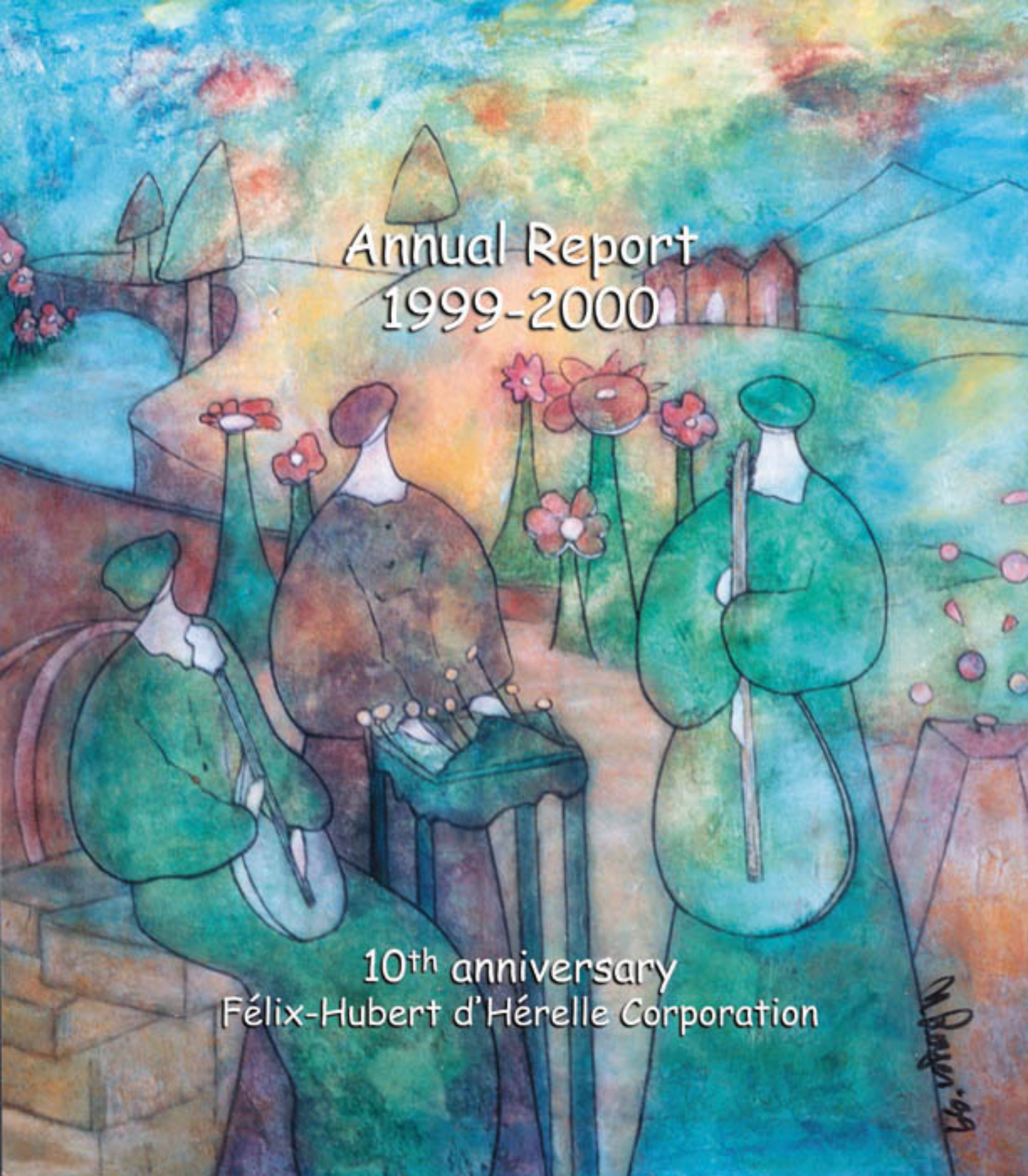

Annual Report
1999-2000
10th anniversary
Félix-Hubert d'Hérelle Corporation

ANNUAL REPORT
1999-2000

Tenth anniversary

The Félix-Hubert d'Hérelle Corporation

Collaborations

The entire team of la Maison d'Hérelle contributed to this annual report in the collection of all the information pertaining to their individual responsibilities.

Editing and corrections

Mireille Falardeau

Page setup

Mireille Falardeau and Jean-Yves Blanchard

Cover illustration:
Artist Madeleine Royer
Montreal (514) 725-9620

The Félix-Hubert d'Hérelle Corporation is a non-profit organization created through a joint initiative of the Quebec Ministry of Health and Social Services, the City of Montreal and Centraide.

The 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.

This annual report concerns the Corporation's 1999-2000 fiscal year, which began on April 1st 1999 and ended on March 31st 2000.

TABLE OF CONTENTS

Word from the Executive Director

Attempting a retrospective look at the ten years of existence of la Maison d'Hérelle is like undertaking a long journey. You could almost make a movie of this journey, to show the world over ! In viewing this, you could then rewind, fast forward and freeze frame on a particular image, to capture some shapes, some sounds, the reflection of a moment but mostly, you could capture some gazes...

In the Fall of 1989, the founders had already been at work for a year to set up a «transition» house for people living with HIV-aids. Originally, the name of the resource was La Salamandre, as is indicated in the charter. It was subsequently that the name was modified to la Corporation Félix-Hubert d'Hérelle.

At the time, there was a crisis to address and the needs were urgent. We were in a state of near panic at the sudden awareness of the limitations of home and hospital care. We were fearful of aids and its ability to spread, we pointed to the homosexual community and we segregated it. In fact, the gay community had to fight to gain access to resources such as ours.

Faced with this situation, the then-mayor of Montreal realized the importance of assisting financially in the renovation of number 3738, St-Hubert street. For her part, Mme Lavoie-Roux of the Ministry for Health and Social Services committed some recurring funds to offset the operating costs of la Maison and Centraide, for its part, chose to contribute to the volunteering aspect of the resource. It was a promising start with all this political goodwill, which is a rare occurrence these days!

Louis-Paul Thauvette, who oversaw the set-up of the project, followed through with the birth of la Maison d'Hérelle and the first resident was welcomed in May 1990. We had assumed that most residents would convalesce shortly at la Maison d'Hérelle and would then return home or would end their days at the hospital. Everything changed when our second resident expressed a desire to live out his days at la Maison d'Hérelle, not at the hospital. This tendency became generalized and the majority of residents sought to remain with us to face the end of their life.

Those years taught us how to live with death. Nonetheless, la Maison d'Hérelle was a place full of life where the team, the volunteers and the loved ones of the residents did their utmost to maximize the quality of life of those who were near the end of theirs.

Six years ahead, in order to address the growing number of requests for admission, the acquisition and renovation of the adjacent property enabled us to pursue our mission and

increase our capacity to welcome up to 17 people. It was at this time that was announced the imminent arrival of some promising remedies to help with the fight against aids. 1996 was a year full of change and adjustments for the team of la Maison d'Hérelle.

Since that time, living with aids has a different connotation and people are now living longer. For many in fact, the new therapies have allowed a true return to life. Hope is now available to our residents. La Maison has been radically transformed. We are witnessing a clear improvement in the health of many of our residents. It is an extraordinary development and we must rejoice in it.

As outlined by the founders, the initial goal to create a transitional community housing resource for people living with HIV-aids is now a reality. For many, loss of autonomy is temporary. What a challenge for all of us! How must we manage to alter our actions and gestures, developed in the context of palliative care? How must we go about applying physical and social rehabilitation methods all the while maintaining our expertise with end of life care for those who are still dying of aids?

We must also deal with the new facets of our clientele. Many carry the burdens of poverty, isolation and social dismissal. We welcome people from all ages, from very diverse cultural and social backgrounds, who no longer benefit from the compassion of their surroundings.

How do we face the decreasing interest in the fight against aids, now that death is no longer the only final outcome? How do we sustain this emotion that has fuelled our indignant passion all these years? How do we make all the necessary adjustments in these rather tumultuous times of redefined roles and reallocated budgets within the healthcare network? These are some of the questions which concern us and to which we must find answers collectively.

In conclusion, I wish to thank all those who have contributed to the life of la Maison d'Hérelle over the last 10 years. I wish to highlight the quality of the work and the devotion of the team during the course of this transitional year and thank the members of the Board of Directors for their involvement.

Thank you to Françoise for her passion in making our book «ÊTRES AUX PASSAGES DE LA VIE» a reality. Thank you for sharing this experience with me. Thank you to Anne and Don also for the construction of the web site. These two endeavours enabled us to meet our objective of making la Maison d'Hérelle better known to the public.

I hope our passions continue to enflame us, to inspire our thoughts and questions and that we be uplifted by the hope of one day defeating the illness that afflicts people living with HIV-aids.

Thank you to all who have contributed to building this resource which makes a difference. Thanks for pursuing the transformation.

Michèle Blanchard

Word from a resident

I arrived at la Maison d'Hérelle in December 1998, to die there. From that moment on, little by little, I made a comeback. A slow, but remarkable comeback. So, I tried a second round of tritherapy. Now, I can say that if la Maison d'Hérelle had not taken me in, I would not be here today.

La Maison d'Hérelle has brought me peace of mind, offered a support system, allowed for new friendships to develop and, of course, has brought me better health.

Living in a large group is not easy! In particular when you're ill and usually a loner. But I learned to appreciate the fact that many people does not have to mean too many people. I have learned to appreciate the relationships that have developed.

There have been difficult moments, and one particular dark period. La Maison d'Hérelle was there all along the way. I owe much to Michel, my main caregiver, who supported me morally and who took the time to sit with me and help me see things with a different eye, with the greatest of respect for me, without making any judgements. And for all this, I tip my hat to him.

La Maison d'Hérelle is a place of hope. Most people that come here have given up hope and many rediscover a taste for life. Here, we are treated as people, not as patients. It is this that makes all the difference.

I am preparing my return to an apartment in July. Despite the highs and lows of my stay at d'Hérelle, the human side of this place will remain my most cherished memory. It is a House where I was welcomed and listened to.

Anick

Word from a volunteer

I am a volunteer at la Maison d'Hérelle since January 1992. It has been over eight years that I have come every week to support the care workers in their tasks with the residents, and sometimes, to support the care workers themselves.

Trained as a nurse, I was attracted to palliative care. I appreciated the authenticity of people reaching the end of their life: they don't play games and they share with you what they are going through with such sincerity. I learned to listen, to feel the richness of silence. I remember every single person I have known, along with a multitude of details that make the quality of a relationship.

There was a turning point, in December 1996. La Maison grew larger and opened its doors to 17 people, instead of the 11 at the start. Then, progressively, the clientele changed. Fewer people in terminal phase, more people in transition. More people suffering from drug addiction too. It was then that I re-evaluated my place at la Maison d'Hérelle. I wasn't sure if I was comfortable with developing new means of accompaniment. Eventually, little by little, I became attached to some other residents and I discovered new ways of helping. I learned that in order to discover someone's universe, you must put your heart into it, without judgement.

If I volunteer, it is because I feel Life has treated me well, and it is my way of saying thank you. What is most extraordinary is that the more I give, the more I receive...the more I love, the more I am loved in return.

Jacqueline

Words from the team members

I have been a care worker for the residents for eight and a half years. Looking back, I find today the very same fundamental values I discovered so long ago: authenticity, support for one another, compassion, unconditional love, laughter, tears, transformation, respect for cultural, spiritual and sexual differences.

I am continuously grateful for the privilege that is given to me to accompany people living with HIV-aids in their quest for a better quality of life.

I thank all of those who have passed through d'Hérelle, who have found peace and who allowed me to accompany them.

Judith

Nearly eight years ago, la Maison d'Hérelle came into my life. Originally, I though of volunteering, then of doing a stage in massotherapy and ultimately, through a number of circumstances, I was hired to be secretary. At the time, to be afflicted with aids meant dying in a more or less short period of time.

More than a simple work environment, I discovered the human experience in all its dimensions, even those that we seek to hide or that we discuss only in whispers. The feeling that I was contributing in my little way to society provided a sense of satisfaction that was unknown to me until then.

Undoubtedly, la Maison d'Hérelle takes care of its residents, accompanies them along their paths whether it be towards life or death, but the employees are not ignored. Life has by no means been a long, quiet river during these years, but I was allowed to pass through the turbulence and I was given respect as a person. I went elsewhere for a time but the quality of the relationships developed with my colleagues and with the residents as brought me back to community life. A great piece of my heart is here…

Anne

I have seen much distress in the last ten years in the residents of la Maison d'Hérelle. It does not always appear in the same form, but it can be seen in the gaze of every person I have encountered.

I believe it is essentially the kindness, the generosity and the availability of the personnel and the volunteers that have contributed to alleviate the suffering of the people who have come through here. The tremendous respect granted to each individual, whether they be a resident or a member of the team, makes la Maison a place where human values are actually experienced.

I have lived through many changes. There as been no shortage of challenges to adapt to. But this Maison is in my view a stimulating and enriching environment and I hope to be around to face the challenges to come...

Michel

1. Ten years … of passages

Complementary or «alternative» approaches to health care

At la Maison d'Hérelle, residents are cared for either by a physician working out of a CLSC who visits regularly or by a physician working out of a private clinic or a hospital. They have access to the latest treatments available and some may even have the opportunity to participate in research protocols for the testing of new medication.

We have always respected our residents' choice of treatment and physician but we have also always been open to complementary treatments, which are sometimes considered «alternative» and which have a positive impact on their health and both psychological and physiological benefits. The use of various means to accompany the treatments received by people living with HIV-aids have been part of our intervention for nearly ten years.

Thus for several years, we have not hesitated to use various therapeutic measures on top of treatments offered to people with HIV.

> *Here's one simple definition : those medical practices that fall outside conventional Western medicine. Complementary therapies include mind-body therapies, in which the power of the mind or the spirit is harnessed to heal the body...*
>
> *...some people prefer the term alternative medicine to complementary therapies, and the abbreviation CAM (complementary and alternative medicine) is being used increasingly.* [1]

These so-called «alternative» and complementary approaches are part of our global approach with residents and are offered to those nearing the end of their lives as well as those recovering, when they ask for them.

The process is founded on the needs that are expressed by the residents. The approach is a global perspective on health. Some of the methods have provided a useful

[1] Catie, A Practical Guide to Complementary Therapies for people living with HIV, 1999, p.2,3.

complement to our residents by providing them with a chance to acquire better control over their power of transformation. Indeed, some can not suffer or do not respond to certain medical therapies. Others suffer ill effects from the medication. Finally, some others simply refuse traditional therapies.

The constant concern of la Maison d'Hérelle has been to be able to offer the widest possible array of treatments. Our first steps were offering massage therapy : we arranged a particular area and offered basic techniques to our care workers. Progressively, we started making use of some special foods and plants. These were prepared either as herbal tea or *decoction*. Essential oils were used for massages. These means provided much relief for some of our residents. Over the years, we experimented with other approaches thanks to the regular contributions from volunteers, trainees and several members of our staff : reflexology, acupuncture, Chi Qong, art therapy and for many years, musical therapy, visualization, massage, shiatsu, meditation and therapeutic touch.

For some time now, our expertise has crossed the walls of la Maison d'Hérelle where some members of the alternative approaches committee have been solicited for training of sufferers and those caring for them, as well as those working in palliative care. Furthermore, many trainees come to la Maison d'Hérelle specifically because of their interest in these methods.

We encourage the team members to take advantage of these methods for themselves, whether it be to take the time to meditate, to savour a massage or to use essential oils or plants. These measures are part of a philosophy of care in which we also learn to care for ourselves.

On particular situation illustrates well the way we integrate these approaches.

Fabien arrives at la Maison d'Hérelle very agitated, speaking constantly, his arms and legs flailing continuously even during rare moments of sleep. Someone must constantly be at his side. Team members and loved ones have to take turns regularly to be with him, so much his state is physically draining. We proposed to his partner and family members to add some simple and reassuring methods to complement his medication. «Anything to help him» they all respond.

Fabien reacts well to massage, touch is appeasing to him. New avenues are attempted to calm his state of extreme agitation, some of which are inspired from shamanism. Amongst these, physical presence, close attention, basic care, creativity and human warmth deployed around him finally pay off.

After a few weeks, Fabien progressively regains some autonomy and returns home, despite a few limitations. Recently, he came back to see us, on his own, using public transportation. What an encouraging pleasure for us and an inspiration for the other residents !

Our experience of openness, attention, human contact and love for our residents has confirmed to us the value of these approaches. Medication alone is insufficient. We have realized that other factors come into play and we take this into account.

This year, we chose to integrate a whole new dimension to our work : we will develop self-care, based on some ancestral healing methods. This approach will gain in importance throughout the year since we have received financial support from Health Canada for it's try-out.

In conclusion, ten years ago, we were the target of all sorts of comments regarding our choice to integrate methods such as massage, meditation, controlled breathing, visualization and the use of medicinal plants. Their benefits are now more and more recognized. Now, with our acquired experience, we dare to try something new again !

The results we obtain and the response from the residents push us forward and motivate us to continue our day to day pursuits.

Offering care... behind the scenes

To an outsider, the work of the maintenance staff can seem very much a routine and, by nature, it almost has to be: every day, picking up, cleaning, see to the repair of one piece of equipment or another, respond to the needs of one and all, let alone the unexpected. This is only the surface of the work, the hidden side reveals an entire set of relationships with the residents in regards to their personal needs. The actions of the maintenance people are sometimes a cornerstone in the reconstruction of the residents' autonomy. They take an active part in the care strategy for each resident.

Often, the maintenance staff are the first to gain regular contacts with new residents. On arrival, the new residents often rely on them for some of the details of their settling in. Whether it be for the layout of furniture or the decoration of their space, they contribute frequently in the familiarization of residents in their environment.

Myriam and Reynald are in charge of maintenance at la Maison d'Hérelle. Residents naturally gravitate towards one or the other, according to their affinities and personality. After an initial time of getting to know one another, a relationship develops allowing a discovery of each person's habits. Primarily, the tasks of the maintenance staff revolve around the cleanliness of the house and the functionality of the equipment. Though they constitute their personal space, the rooms of the residents are also part of the space that requires housekeeping.

Depending on their physical and psychological state, the upkeep of their room is a considerable task for the residents. We try to work realistically within the limits and capabilities of each individual. Indeed, we cannot expect the same from a person in a state of homelessness than from one who has been used to the comforts of a well-equiped apartment. The objective of the maintenance people is to work together with the residents, in other words to encourage them to do as much as they can for and by themselves, and to support them for the rest.

Furthermore, the ethnic origin as well as the social and cultural background of each resident will outline various habits that have to be taken into account, when establishing a plan for the upkeep and housekeeping of the residents quarters. Because of the nature of the illness that afflicts the residents, certain steps have to be taken to ensure proper hygiene. Despite all this, we must adapt our expectations in accordance with each person and their origins when it comes to some less essential hygiene precautions.

With great respect for these variances, the maintenance personnel often work behind the scenes but they listen a lot and are bearers of many precious confidences. Whether it be the anguish of one regarding an eventual return to life in an apartment, the fear of another at the progression of the illness or the anger of yet another at the side effects of the medication, they lend an attentive ear to residents who need to confide in someone or simply to talk. The upkeep of the environment is often a path which opens the way to the establishment of a trusting relationship.

Always respecting the individual and their state of health, the maintenance staff can motivate a resident to accomplish certain small tasks in their room or join them in the housekeeping of their environment. One example was a resident depressed with her state of health and her situation in general, who often refused that the staff enter her room to clean it, with the result that it was in a considerable state of disarray. With some gentle persuading, she eventually accepted Myriam's help and together, they cleaned and rearranged her room. After this, we noticed a progressive change in the attitude of this resident. She took over the upkeep of her room, decorated it and began to care for her physical appearance. We have noted a distinct correlation between the personal space of the residents and their psychological state, and in some cases, their physical state.

The previous example illustrates well the active participation of the maintenance staff in the development or the improvement of the residents' self esteem. Through patient reinforcement and in recognizing the efforts made by a resident, they have the opportunity to contribute to their developing a general sense of competence in life. They play a supporting and educational role in the process of regaining control of the small daily tasks, so essential to reaching autonomy. The residents thus discover the power that they actually have over their environment and their life.

As we have seen, the work of the maintenance personnel consists not only in assuming the daily tasks of the upkeep of the house, but also include other aspects of the care for the residents. Right from the moment they arrive, the residents develop a relationship with them allowing for some mutual trust to arise. More and more, residents come to la Maison d'Hérelle as a transition period during which they hope to regain sufficient autonomy to return to their life in the community. With the work that they do on the level of the basic upkeep habits of the residents, the maintenance staff are almost certainly key players in any social reintegration project.

Anne Véronneau
With the maintenance team

The kitchen and the dining room

Two years ago, we reported on the original impact of tritherapy on the atmosphere of the dining room and on our tasks as cooks. The relatively increasing health of a portion of the clientele had already began to modify the role of the kitchen, which up to that point had been adapted to the needs of terminally ill residents. Since that time, the trend has been confirmed; we generally cook meals for the benefit of convalescing people. It is to say that diet has taken an increasingly important place in the concerns of la Maison d'Hérelle. Indeed, as much for the residents as for ourselves, the dining room has become a central instrument and place to regain one's health.

No great discussion has to take place regarding the relationship between diet and health in order to understand our mandate to serve our clientele some healthy, balanced, tasty meals. As obvious as it seems, this was nonetheless one of the most fascinating challenges we were faced with this year: personal taste, consuming habits and cultural diets do not necessarily equate to high quality balanced diets.

Against all expectations, we were forced to ask ourselves a serious question: should we revise our objectives of healthy dieting in accordance to the preferences of our clientele? Though no one amongst our residents questioned our competence, we nonetheless witnessed a paradox which we chose to dub the French Fry effect and the Garbage Can effect, to designate the increasing demand for «fast food» and the systematic rejection of our cuisine, which unceremoniously went the way of the garbage...

Give in or stand our ground? This dilemma forced us to examine more closely the relationship that some of our residents, in particularly those suffering from drug addictions, had with food. After some discussions, some examinations, some listening, some comments amongst ourselves and with residents, we were able to come to one important conclusion: eating healthy is first and foremost a question of trust. And this trust is by no means something that was granted to us freely.

«I don't like it when I can't tell what I'm eating.»
«It doesn't taste like...my mom's...like McDonald's...»
«Who are you to tell me what and how to eat?»

Amongst the comments offered by our residents as they were handed their meals, some caught and eventually held our attention. It was all about what is in the plate that you can't see: the spices, the food hidden under sauces, the mashed vegetables or the ones mixed in broth, etc. Conversely, we realized the appreciation residents obviously had

for soups containing clearly identifiable vegetables, clear sauces and meats that left no doubt about their nature. Food therefore has to be straightforward, otherwise it runs the risk of being treated suspiciously as much for its taste, its benefits healthwise or for other considerations more or less related to the process of eating.

Trust and mistrust issues also dance around flavours : some are trustworthy others are not. Pâté chinois, especially if it tastes “as good as mom's”, takes the prize as well as standard restaurant food which we've become accustomed to in adulthood and which is always trustworthy: you go to St-Hubert BBQ, things will taste just like St-Hubert BBQ!

If these considerations have brought us to give way somewhat to fast foods, they have mostly brought about a dialogue around the issue of food between those who make it and those who eat it. If eating is first and foremost a question of trust, it seems as though this trust is taking root around certain desires worth sharing: the desire to eat, the desire to cook and the desire to talk about both.

Claudette Isabelle

A publishing event

Last October, we celebrated the launch of a book authored by members of the team of la Maison d'Hérelle.

«Êtres aux Passages de la Vie»* is a depiction of all of us, through a look at our relationships and our day to day concerns. It is the story of a resident, Marcel, but it is also the story of Marie, a care worker, and many others as well, who work here at la Maison d'Hérelle.

It is about their encounters, their questions, their joy and sorrows, throughout the transitions that we go through in life.

Françoise Moquin

* MOQUIN, Françoise ; BLANCHARD, Michèle, *Êtres aux Passages de la Vie*, Samsarah Rainbow Planet , 1999, 186p .

2. Portrait 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;
- To undertake to respect rules of participation and community living.

The following pages outline :

- a global look at the evolution of the clientele ;
- statistical data on the profile of residents in the last two years (1999 – 2000 and 1998 – 1999) as well as cumulative data compiled since the opening of the resource (1990 – 2000) ;
- data regarding requests for admission ;
- a "compilation" of the services offered to loved ones (partners, family and friends) of the residents.

Evolution of the clientele

Analysis of the collected data from the files of the residents between 1990 and 2000 allow us to make a number of assumptions.

Number of residents

Since the opening of la Maison d'Hérelle in May 1990, we have welcomed 246 residents. This year, 48 people stayed at la Maison. There were 35 admissions during the course of the year, the 13 others were admitted prior to the 1st of April 1999.

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

Age at admission

In the last 10 years, the average age has remained relatively unchanged at approximately 45 years old. The majority (63%) are between 30 and 45 years old.

Gender

Since the opening, la Maison d'Hérelle has welcomed a great majority of men: more than 88% over ten years. This year, 20% of our clientele consists of women. In the last two years, our female clientele has increased significantly.

Sexual orientation

Between 1990 and 1997, less than 12% of our clientele was heterosexual and this a steady constant. In the last three years, this has increased to 32% (1997 – 1998), 54% (1998 – 1999) and 40% this year. Over the last two years statistically, the number of heterosexual residents has surpassed the number of homosexuals. This is one of the most significant changes in our clientele.

We have also denoted a new fact this year: nearly 63% of our residents have children. This is a completely new phenomenon and has completely transformed the dynamics of

community environment. The team has had to take this into account on several occasions in order to properly integrate children into the day to day life of la Maison.

Type of care

Over the last two years, 77% of our residents were undergoing antiretroviral therapy on a regular basis: 27 residents out of 35 last year and 37 out 48 this year. This reality has had a direct effect on the needs of the clientele. Residents in transition are increasing steadily:

0 between 1992 and 1997 ;
5 in 1997 – 1998 ;
11 in 1998 – 1999 ;
14 this year.

Furthermore, 2 residents admitted for palliative care finally gained sufficient autonomy to consider returning home. Conversely, 2 persons admitted for transition care took a turn for the worse: they both passed away during the course of the year.

Reasons for departure

Last year, only four of our residents passed away. This year, 12 died during the course of their stay and 2 more, after their admittance at the hospital.

44% of our residents returned home.

Occupancy rate

Palliative care and transition:

Number of days	5 042
Total capacity (16 beds X 365 days)	5 856
Percentage of occupation	**86,1%**

Short term care:

Number of days	180
Total capacity (1 bed X 365 days)	366
Percentage of occupation	**49,2%**

Associated afflictions

We denoted an increase in the number of hepatitis cases this year, but a decrease in the number of PPC and toxoplasmosis. On the other hand, we have had, for the first time, 5 people suffering from cirrhosis.

The increase in the number of residents suffering from drug addiction is yet another noteworthy change in our clientele: 63% of the residents are afflicted.

Note that furthermore, it is often difficult to make the distinction between symptoms that may be related to neurological trouble and those associated with mental health problems.

An overview

Our analysis is comparable to the data reflecting the Quebec population afflicted with aids. Following is a number of statistics taken from a publication of the *Direction générale de la santé publique du Ministère de la Santé et les Services sociaux*, entitled *Surveillance des cas de syndrome d'immunodéficience acquise* (*SIDA*), Quebec, up to date December 31st 1999 :

- People aged between 25 and 49 are most afflicted, representing nearly 85% of all reported and confirmed cases in Quebec ;
- Among the cases confirmed, men account for 88.5% of all cases, as well as 85.4% of all diagnosed cases in 1999 ;
- Homosexual and bisexual men remain the most afflicted groups, accounting for 64% of all cases and 72% of newly reported and confirmed cases as of December 31st 1999 ;
- Heterosexual IDUs[📖] make up 6.6% of the total reported and confirmed cases in Quebec ;
- Intravenous drug usage amongst the aids afflicted population is increasing notably amongst women, moving up from 12.5% before 1995 to 37% in 1998 and 33% in 1999 ;
- The principal categories of exposure for women are « country of origin » 37%, heterosexual contacts 26% and IDUs 17%.

Mireille Falardeau

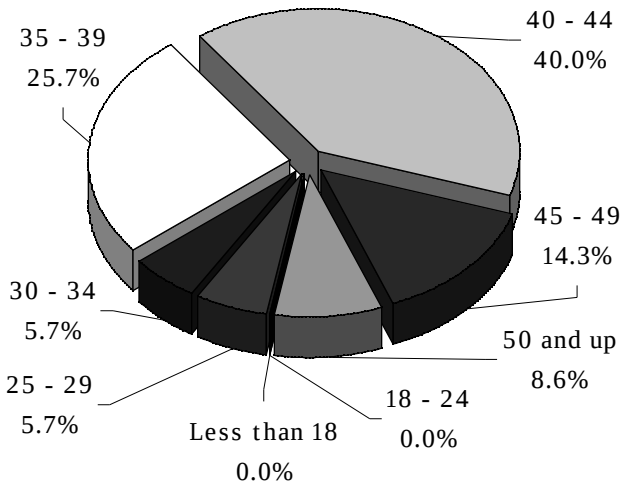
📖 IDUs : Intravenous Drug Users

Profile of the residents

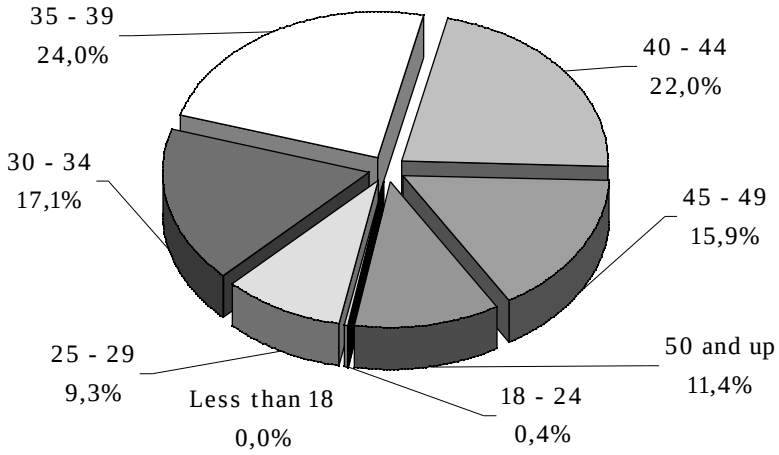
Age

	1999-2000	%	1998-1999	%	1990-2000	%
Less than 18	0	0,0%	0	0,0%	0	0,0%
18 - 24	0	0,0%	0	0,0%	1	0,4%
25 - 29	2	5,7%	1	2,9%	23	9,3%
30 - 34	2	5,7%	6	17,1%	42	17,1%
35 - 39	9	25,7%	8	22,9%	59	24,0%
40 - 44	14	40,0%	3	8,6%	54	22,0%
45 - 49	5	14,3%	4	11,4%	39	15,9%
50 and up	3	8,6%	4	11,4%	28	11,4%
Total	**35**		**26**		**246**	
Average age upon admission	**41,0**		**41,6**		**39,7**	

1999-2000



1990-2000

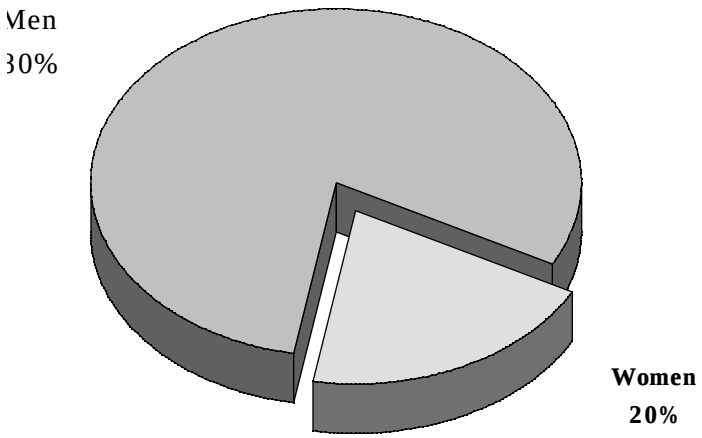


Gender

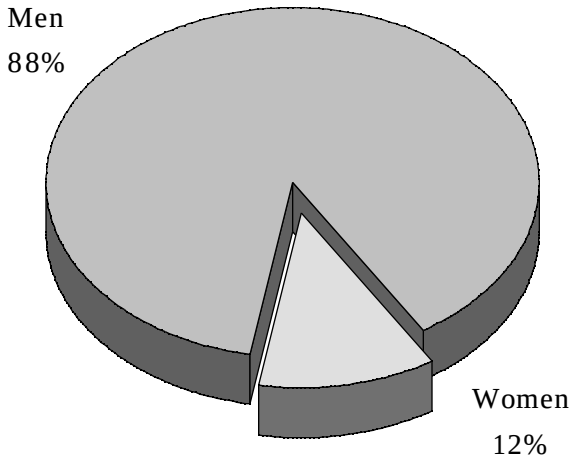
	1999-2000	%	1998-1999	%	1990-2000	%
Men	28	80,0%	20	57,1%	217	88,2%
Women	7	20,0%	6	17,1%	29	11,8%
Total	**35**		**26**		**246**	

Note: Amongst the men, one person had a feminine identity and was in the process of transgendering.

1999-2000



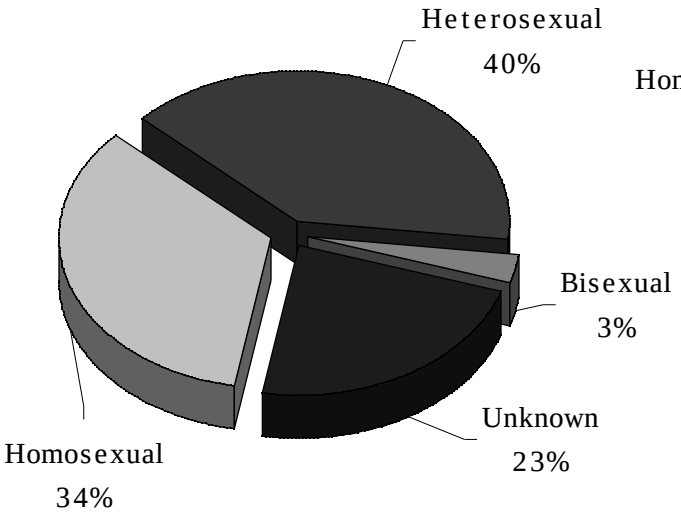
1990-2000



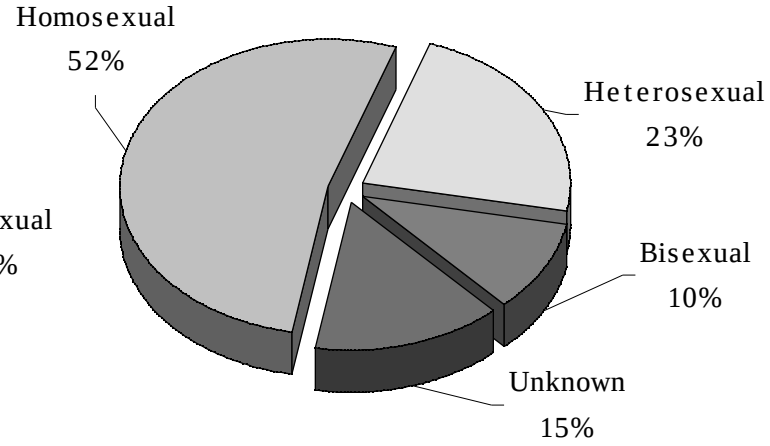
Declared sexual orientation

	1999-2000	%	1998-1999	%	1990-2000	%
Homosexual	12	34,3%	10	28,6%	129	52,4%
Heterosexual	14	40,0%	14	40,0%	56	22,8%
Bisexual	1	2,9%	2	5,7%	25	10,2%
Unknown	8	22,9%	0	0,0%	36	14,6%
Total	**35**		**26**		**246**	

1999-2000



1990-2000



Family life

	1999-2000	%	1998-1999	%	1990-2000	%
No children	13	37,1%	15	42,9%	179	72,8%
With children	22	62,9%	11	31,4%	67	27,2%
Total	**35**		**26**		**246**	

Ethnic origin

	1999-2000	%	1998-1999	%	1990-2000	%
Canadian	30	85,7%	22	62,9%	218	88,6%
Haitian	2	5,7%	1	2,9%	12	4,9%
Other	3	8,6%	3	8,6%	16	6,5%
Total	**35**		**26**		**246**	

Note: Others (1990 to 2000): Chilean (3); French (2); Greek (2); Cuban (2); Nicaraguan (1); Romanian (1); German (1); Portuguese (1); East Indian (1); Colombian (1); Vietnamese (1).

Mother tongue

	1999-2000	%	1998-1999	%	1990-2000	%
French	26	74,3%	22	62,9%	188	76,4%
English	4	11,4%	0	0,0%	32	13,0%
Creole	2	5,7%	1	2,9%	12	4,9%
Spanish	2	5,7%	2	5,7%	7	2,8%
Other	1	2,9%	1	2,9%	7	2,8%
Total	**35**		**26**		**246**	

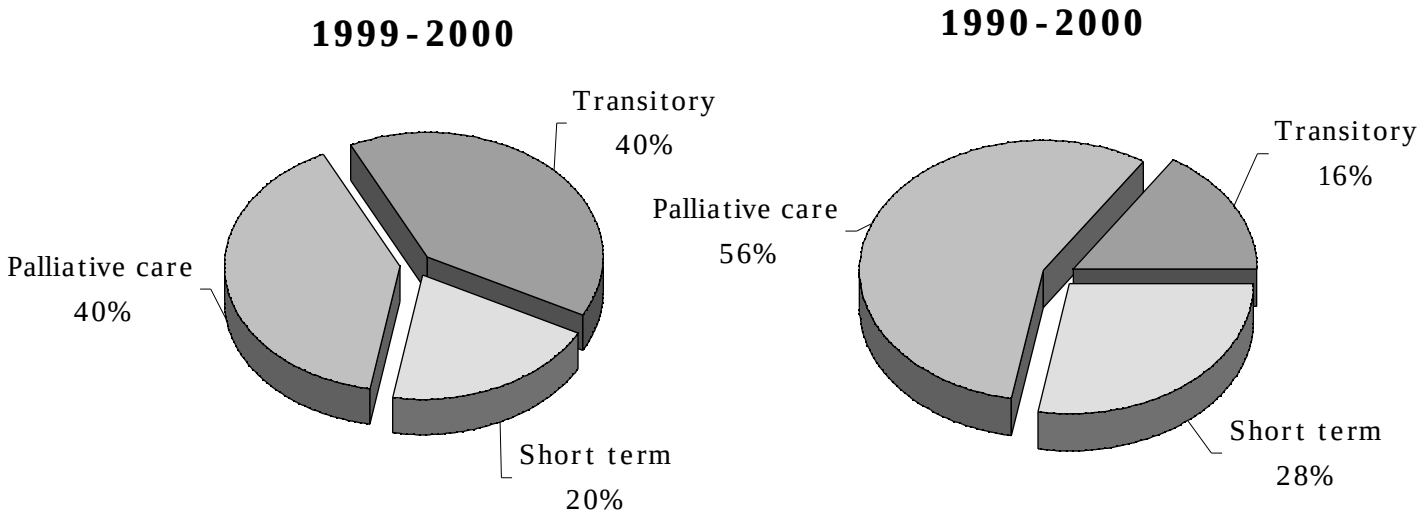
Note: Others (1990 to 2000): Greek (2); Romanian (1); German (1); Portuguese (1); Punjabi (1); Vietnamese (1).

Financial resources upon admission

	1999-2000	%	1998-1999	%	1990-20000	%
Social welfare	24	68,6%	17	48,6%	149	60,6%
Salary insurance	1	2,9%	2	5,7%	38	15,4%
Quebec Pension Plan	1	2,9%	3	8,6%	23	9,3%
Unemployment insurance	1	2,9%	1	2,9%	9	3,7%
Workers' compensation	0	0,0%	0	0,0%	1	0,4%
RRSP	0	0,0%	0	0,0%	1	0,4%
Other	2	5,7%	3	8,6%	9	3,7%
Unknown	6	17,1%	0	0,0%	16	6,5%
Total	**35**		**26**		**246**	

Type of care

	1999-2000	%	1998-1999	%	1990-2000	%
Palliative care	14	40,0%	7	20,0%	139	56,5%
Transitory	14	40,0%	11	31,4%	39	15,9%
Short term	7	20,0%	8	22,9%	68	27,6%
Total	**35**		**26**		**246**	



Hospitalisation(s) during stay

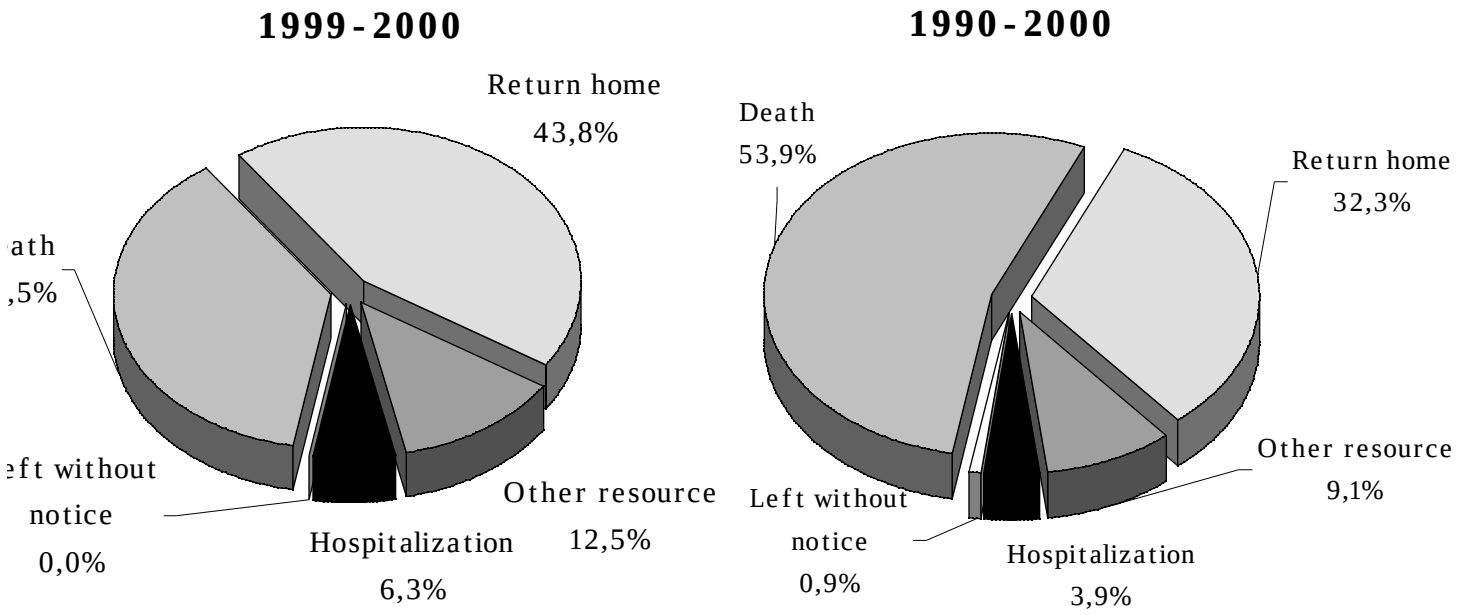
(from this point on, statistics concern residents that have ended their stay)

	1999-2000	%	1998-1999	%	1990-2000	%
None	23	71,9%	17	53,1%	163	70,3%
One	4	12,5%	7	21,9%	44	19,0%
Two	3	9,4%	2	6,3%	19	8,2%
Three	1	3,1%	0	0,0%	4	1,7%
Four or more	1	3,1%	0	0,0%	2	0,9%
Total	**32**		**26**		**232**	

Reasons for departure

	1999-2000	%	1998-1999	%	1990-2000	%
Death	12	37,5%	4	12,5%	125	53,9%
Return home	14	43,8%	20	62,5%	75	32,3%
Other resource	4	12,5%	2	6,3%	21	9,1%
Hospitalization	2	6,3%	0	0,0%	9	3,9%
Left without notice	0	0,0%	0	0,0%	2	0,9%
Total	**32**		**26**		**232**	

Note: 2 resident died soon after their hospitalization.



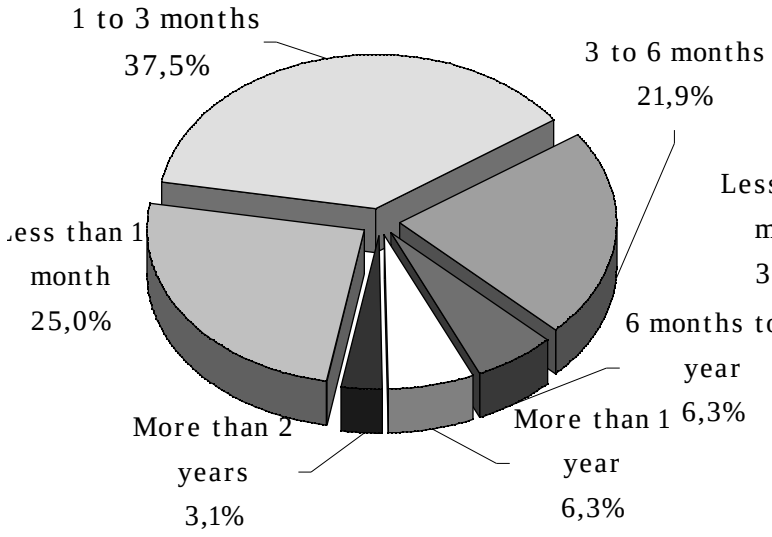
Place of death

	1999-2000	%	1998-1999	%	1990-2000	%
Maison d'Hérelle	9	75,0%	3	25,0%	109	87,2%
Hospital	3	25,0%	1	8,3%	16	12,8%
Total	**12**		**4**		**125**	
Average age at death	**42**		**45**		**40,7**	

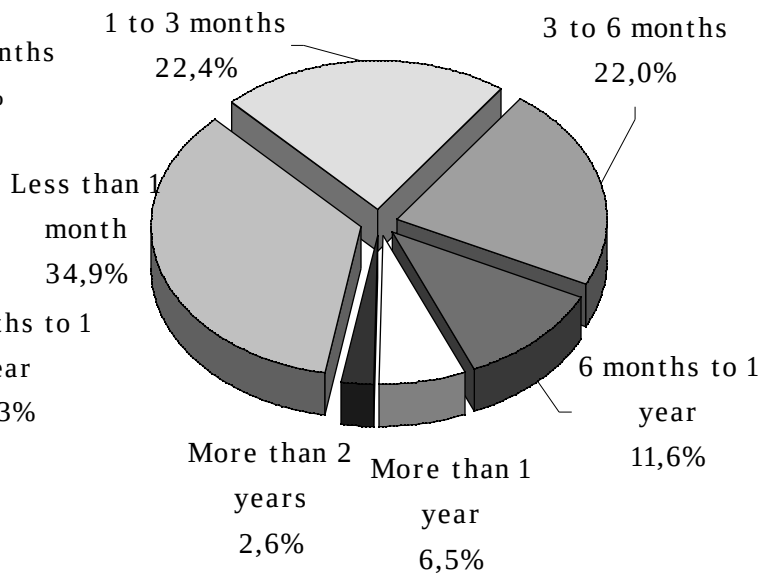
Length of stay

	1999-2000	%	1998-1999	%	1990-2000	%
Less than 1 month	8	25,0%	8	25,0%	81	34,9%
1 to 3 months	12	37,5%	2	6,3%	52	22,4%
3 to 6 months	7	21,9%	6	18,8%	51	22,0%
6 months to 1 year	2	6,3%	6	18,8%	27	11,6%
More than 1 year	2	6,3%	2	6,3%	15	6,5%
More than 2 years	1	3,1%	2	6,3%	6	2,6%
Total	**32**		**26**		**232**	
Average (in months)	**4,34**		**7,50**		**4,74**	

1999-2000



1990-2000



Average length of stay per program

1999 - 2000

Palliative care	**4,5 months**
Transitory	**6 months**
Short terms	**38 days**

Associated afflictions

	1999-2000		1998-1999		1997-1998	
Total number of residents	**48**	**%**	**35**	**%**	**46**	**%**
Candidosis	28	80.0%	20	57.1%	20	43.5%
Cryptococcosis	2	5.7%	1	2.9%	1	2.2%
Cytomegalovirus (C.M.V.)	8	22.9%	4	11.4%	8	17.4%
Dementia (atteinte cognitive)	2	5.7%	1	2.9%	3	6.5%
Depression	10	28.6%	7	20.0%	13	28.3%
Encephalopathy / leucoencephalopathy	20	57.1%	16	45.7%	12	26.1%
Hepatitis	17	48.6%	8	22.9%	10	21.7%
Herpes	5	14.3%	4	11.4%	6	13.0%
Recurring bacterial infection	1	2.9%	2	5.7%	1	2.2%
Lymphoma	2	5.7%	0	0.0%	4	8.7%
Mycobacteriosis (M.A.I. / M.A.C.)	2	5.7%	3	8.6%	3	6.5%
Paralysis	3	8.6%	1	2.9%	3	6.5%
P. carinii pneumonia	11	31.4%	12	34.3%	16	34.8%
Bacterial pneumonia	2	5.7%	3	8.6%	3	6.5%
Kaposi sarcoma	7	20.0%	5	14.3%	8	17.4%
HIV emaciation syndrome	3	8.6%	3	8.6%	6	13.0%
Drug addiction	22	62.9%	16	45.7%	23	50.0%
Toxoplasmosis	4	11.4%	5	14.3%	7	15.2%
Behavioral troubles	6	17.1%	4	11.4%	5	10.9%
Mental health problems	8	22.9%	5	14.3%	10	21.7%
Pulmonary tuberculosis	0	0.0%	0	0.0%	1	2.2%
Zona	3	8.6%	7	20.0%	6	13.0%

Notes:

Others (1999 - 2000): Cirrhosis (5)

These afflictions reflect the annual portrait of the clientele

The data is collected from the physician's notes in the residents files for all the residents who came to la Maison d'Hérelle for each year indicated

Admission requests

This year, the Admissions Committee began an adjustment of its functions, in order to address the new realities that are emerging. For more than two years now, our clientele has been plagued with an increasing amount of affliction related to drug addiction, mental health, homelessness, etc.

During the course of the year, we received several requests from within the carceral system. These are generally cases referred to us for palliative care or, more frequently, for transitory care preceding social reinsertion, with requests for evaluation and access to antiretroviral therapies.

We have access to very little information regarding the criminal past of these persons, other than what they are willing to share with us. The risk of aggressive, or even violent, behaviour and conflict with other residents is something we are forced to evaluate on a moment to moment basis. How will this new clientele influence community life at la Maison ? What needs to be done to have the team integrate new intervention methods ?

During the course of the last quarter, approximately 90% of people who requested to be admitted at la Maison d'Hérelle were afflicted with multilevel problems : active multiple drug addictions, poverty, homelessness, criminal past. When the principal affliction is directly related to aids, the admission process is relatively simple, however when other disorders are the principal reason for the care required, we are faced with a dilemma because the sufferer does not meet the admission criteria of other resources.

On the other hand, those other resources are not always capable of being of assistance with the medication intake nor to evaluate the state of health in this context.

The process of pre-admission requires more elaborate steps on the level of psychosocial evaluation. The objectives of the care are conceived in an individual perspective, while estimating as much as possible the pertinence of the stay at la Maison d'Hérelle for individuals who would have difficulty finding another resource to answer to their needs : whether it be related to their HIV status, to their multilevel disorders or because their social reinsertion is improbable in the short term.

We assist the individual in identifying by themselves the means which they intend to take to reach their objectives. The projected length of the stay is also discussed prior to admission. The rules governing day to day personal life must be clearly stated in order for them to be followed. These rules are adaptable to each individual resident, in accordance with their current state. The committee also ensures that the referring

agent (social worker or probation agent) continues to support the individual, after admission at la Maison d'Hérelle.

It is difficult to imagine what admissions requests will be like next year. The situation is evolving quickly in some unforeseen directions. Our work will thus require continued flexibility and a keen sense of adaptability.

Jean-Marc Meilleur and Mireille Falardeau
For the admissions committee.

	1999-2000		1998-1999	
Admissions	27	50,9%	26	49,1%
Admissions waiting list	3	5,7%	7	13,2%
Died before admission	0	0,0%	1	1,9%
Admissions - other resource	20	37,7%	12	22,6%
Withdrawn requests	0	0,0%	6	11,3%
Refused request	3	5,7%	4	7,5%
Total	**53**		**56**	

A great number of additional requests were presented to la Maison d'Hérelle informally: these requests were made to scope out the resource.

Transitory services

Social reinsertion

Nearly 130 hours were vested with 20 residents before their departure from la Maison d'Hérelle in regards to social reinsertion. These mostly comprised the following :

- Identifying specific needs for a proper return home ;
- Psychological support, in particular with the anxiety and uncertainty that accompanies the prospect of returning home ;
- Assistance with the search for financial aid ;
- Assistance with day to day planning ;
- Assistance with progressive independence regarding the intake of medication
- Assistance with the search for housing and furniture ;
- Assistance with administration of financial resources ;
- Search for home care
- Organization of the natural support system;
- Assistance with legal aid ;
- Diet planning ;
- Advice for home upkeep.

A start-up diet package was prepared by the kitchen staff, containing some essentials (with a value of approximately $25). This package is offered at no cost to the residents who need help to better prepare their departure from la Maison d'Hérelle. Some good advice and the types of food to look for (in terms of nutritional value and cost) as well as some simple recipes have all made the send-off a little easier for many residents.

Post-departure follow-up

Nearly 100 hours were vested in 13 residents after they left la Maison d'Hérelle :

- House calls ;
- Help with day to day living ;
- Evaluation of needs and services required for home ;
- Psychological support ;
- Evaluation of autonomy regarding the intake of medication and regarding finances ;
- Conflict resolution (occasionally).

Last year there were more than double the hours spent than this year on post-departure follow-up and social reinsertion, thanks to a subsidy from COCQ-sida in the scope of their «return home» project. The need for these services is ever more present but the lack of financial resources has forced us to cut back on the time allotted to these activities. We hope to catch up to this failing in the coming years.

Mireille Falardeau

Support of close ones of the residents

Service	Persons	Hours
Psychological support	74	546
Information on the progression of the illness	60	205
Advice on care	30	112
Legal support	11	16
Alternative approaches to health care	9	9
Meetings with the physicians	9	5
Social economic support	6	11

Other services

Several reunions occurred this year, for families, for loved ones and for cultural community groups stemming from various needs including the desire to know the state of one resident or another, the need for psychological support, the desire to find out the services offered at la Maison d'Hérelle, the need for a funeral service and finally, for some assistance in the setting up of services surrounding home care.

We must not forget also the more discreet moments of support around a coffee table, in the living room as well the numerous meals served to visitors : we know that this kind of day to day informal support also makes a difference.

Mireille Falardeau

3. Volunteering

Building tomorrow, today

We can observe a decrease in volunteer activities in general in recent years, among our industrialised societies. However, we will not dwell on the complex and numerous reasons for this phenomenon. At la Maison d'Hérelle, we had always found a way to get around the consequences of this fact but now, we find that these are catching up to us.

Though the number of volunteer has remained the same, the hours of volunteering have dropped to 81% of last year's total. This however, represents an astonishing 24 000 hours of devotion and generosity offered by some 438 people throughout the year and this, often, behind the scenes. Each one of these individuals certainly deserve our profound gratitude and we thank them with all our hearts.

These fluctuations though, ultimately, are a good sign. The antiretroviral therapies are bringing about an adjustment of the services offered to the residents and thus, a reassessment of the role of volunteers. This relatively calm period is a preparatory stage in the process of preparing for some new projects that will breathe new life into the volunteer program.

The theme of our annual volunteer week which was held at the beginning of April was «building tomorrow, today». This theme turns out to be particularly accurate. It is a good reflection of what the volunteer movement has become in our industrialized societies and its impact at la Maison d'Hérelle. We can see some new tendencies in the social implication of today's volunteers. Their role is rapidly moving away from the traditional help for the less fortunate and is turning much more in the direction of independent assistance to people they consider their peers. A measure of how far the volunteer movement has come!

Community resources have often been the first to react to social problems : community members, affected directly or from afar by the lag or lack of health services, have always been the ones who together, were preparing today for tomorrow.

In this new year, following the changes in the fight against aids, we are witness to this fact. The services required by the residents are more oriented outward and the role of the volunteers at la Maison d'Hérelle is following suite.

Thus la Maison d'Hérelle, always prepared for some new social challenges, has just submitted a new social integration project to several potential funders, amongst them the Régie régionale de la Santé et des Services sociaux de Montréal-Centre. The project proposes, initially, to offer a post departure service to people living in aids community houses in Montreal. Secondly, it proposes preventive assistance for people living with HIV-aids, in the hope of possibly avoiding community housing as well as diminishing and shortening hospitalizations. The primary mission of the project is to maintain and promote the autonomy of people living with HIV-aids by helping with their social integration. The follow-ups will distinguish themselves from traditional assistance in the fight against aids : they will favour short-term support aimed at maintaining and developing autonomy of those afflicted by guiding them toward external services.

The project proposes a team of care-givers who will do the follow-ups right in the community. The innovation here resides in the volunteer contribution, which will join the effort as a complement to the role of the care-givers. Not only can we sense a desire for more personnalized intervention amongst our volunteers, but many of them who have been involved in our organizations for many years, already posses the required skills to answer this new challenge.

Once again, thank you, to each and every one of them and let us continue to

Build tomorrow, today !

Richard Desjardins

Activities related to volunteering

- 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; zootherapy; etc.
- Socio-cultural activities: planning and organizing, ticket sales, music, etc., kitchen help
- 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

Statistics on volunteering

Sector	Persons	%	Hours	%
Administration	17	3,9%	1 970	8,4%
Alternat	8	1,8%	1 228	5,2%
Alternative approaches	11	2,5%	689	2,9%
Others	256	58,4%	3 237	13,8%
Board of directors	9	2,1%	626	2,7%
Consultants	6	1,4%	168	0,7%
Kitchen	13	3,0%	1 676	7,1%
Intervention	24	5,5%	2 857	12,2%
Personnel	24	5,5%	5 244	22,3%
Employment programs	2	0,5%	1 600	6,8%
Residents and loved ones	51	11,6%	574	2,4%
Trainees (students)	17	3,9%	3 629	15,4%
Total	**438**		**23 498**	

4. Training

Trainees at la Maison d'Hérelle

Student trainees

Sector	Persons	Hours
Special education	9	2 630
Massotherapy	3	52
Social Work	2	672
Nursing	2	240
Musical therapy	1	35
Total	**17**	**3 629**

Work program trainees

Sector	Persons	Hours
Intervention	1	880
Reception and secretarial	1	720
Total	**2**	**1 600**

Training received and offered by the staff

Training received

In order for the team to continue offering quality services that correspond to the current needs of the clientele, several of its members participate in workshops, discussion groups or talks on the various themes associated with the challenges encountered in community housing and the operations of a community resource.

More than 350 hours of training were received by the staff of la Maison. Below are some of the themes that were studied :

- The systemic approach ;
- Managing aggressive behaviour ;
- The symbolic language of conflict resolution ;
- Transgendering ;
- Entrepreneurship ;
- Shamanism and Celtic beliefs ;
- Communication with the media specific to community resources ;
- HIV in the penal system ;
- Personnel management.

This year, we intend to invest some resources on training in the field of management of aggressive behaviour, as this aspect is gaining importance in the general scope of our intervention.

Training offered

We have shared the expertise we acquired over the years through conferences as well as theoretical and practical workshops. More than 80 hours were offered to other resources over the year. The most recurring requests are the following :

- People living with HIV-aids : information and dialogue ;
- Prevention and awareness ;
- Aids and the alternative approaches to health care ;
- Nursing in the context of the aids-community resources ;
- The role of la Maison d'Hérelle ;
- Aids today.

We must also take into account the training we dispense amongst ourselves according to our respective qualifications, the feedback we receive from team members who attend training outside the resource, the exchange of expertise with the health professionals who tend to the residents of la Maison and of course, the more than 200 hours of practical training in-house in regards to the guidance and support of our trainees and volunteers.

Mireille Falardeau

5. Collaborations

We wish to underline the precious collaborations we have maintained or initiated with 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 COCQ-sida, for their support and political representation, their input and the use of their conference room;
- 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 St-Louis-de-France Parish;
- Daniel Bourget, of St-Joseph-du-Lac, for the honey;
- Isabelle Véronneau, graphic artist;
- The Dorothée Minville Pharmacy;
- Interjonction ;
- The Communauté religieuse des Sœurs des Saints Cœurs de Jésus et de Marie, for the presence of Lise Germain.
- Diffusion Raffin.

Michèle Blanchard

6. Financing

Operation revenues

Provincial government	507 117 $
Régie Régionale : The Extra Program	2 000 $
Centraide : volunteer program	102 000 $
Contribution from residents	81 912 $
Donations (voir Principaux donateurs)	89 832 $
Fundraising	18 148 $
Various revenues	8 480 $
Total	**809 489 $**

Principal donors

We wish to thank :

- The Mac Aids Fund
- The Jean-Louis Lévesque Foundation
- The A Contre Courant Aquatic Club
- Teleglobe
- The Bank of Montreal Employees Foundation

Principal fundraising activities

- Les 24 Heures
- Ça Marche – The Farha Foundation

Budget projections 2000-2001

Provincial government	600 000 $
Régie Régionale : social reintegration measures	5 000 $
Centraide : volunteer program	102 000 $
Contribution from residents	85 000 $
Donations	75 000 $
Fundraising	25 000 $
Various revenues	8 500 $
Special programs (Health Canada, Centraide)	17 350 $
Total	**917 850 $**

Michèle Blanchard

7. Perspectives for the future

During the year 2000 - 2001, we will strive to reach the following objectives :

- Take a stand on the mission of la Maison d'Hérelle in light of the new clientele of aids-community housing ;
- Approach funders in the pursuit of the «Social Reinsertion» Project which will ensure the post-departure support for people living with HIV-aids ;
- Gain better understanding and develop innovative approaches regarding social reinsertion ;
- Increase our visibility in the community and in particular with our partners in the aids network and the other groups involved with our residents ;
- Consolidate our financing activities through our participation in the events surrounding our Tenth anniversary
- Continue our pilot project responsibilities through training and support to other resources as well as through conferences and the transmission of documentation and research results.

Michèle Blanchard

Human resources

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
Jean Brien	Administrator
Pauline Desautels	Administrator
François de Beaulieu	Administrator
Jean-Pierre Hogue	Administrator
Jacqueline Chabbert	Representing the volunteers
Michel Barbe Marie-Noëlle Pierre	Representing the residents (each in turn)
Gary McCarrick	Representing ex-residents
Michel Richard	Representing the employees
Michèle Blanchard	Executive director of la Maison d'Hérelle

Employees

The following employees were on staff during the year 1999 - 2000 :

Michèle Blanchard..... Executive Director
Richard Desjardins ..... Volunteering co-ordinator
Anne Véronneau..... Administrative assistant
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 (part time)
Roger Gagné..... Assistant cook (on call)
Stéphanie Lacroix ..... Assistant cook (on call)
Laure Olivier..... Assistant cook (on call)
Pascale Gingras ..... Assistant cook (on call)
Myriam Van Male ..... Maintenance coordinator (part time)
Reynald Mercier ..... Maintenance assistant
Anthony Early ..... Maintenance assistant (on call)
Gary Mc Carrick ..... Maintenance assistant (on call)
Madeleine Royer..... Technical care support
Michel Richard..... Care worker
Judith Dendy..... Care worker
Jean-Marc Meilleur ..... Care worker
Roxanne Landry ..... Care worker
Cindy Raess..... Care worker
Caroline Bibaud ..... Care worker
Denyse Lavigueur..... Care worker (on call)
Carole Durand ..... Care worker (on call)
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)
Ghislaine Roy ..... Care worker (on call)
Joffré Maneli..... Care worker (on call)
Raymonde Paquette..... Care worker (on call)

Denis Bourcier .....Care worker (on call)
André Lortie .....Care worker (on call)
France Desnoyers .....Care worker (on call)
Élise Patenaude .....Care worker (on call)

Trainees

Employment program

Jacques Babeu .....Care work
Renée Lapatrie.....Reception et secretarial

Students

Élise Patenaude .....Specialized education
Geneviève Pellerin.....Specialized education
Isabelle Lévesque .....Specialized education
Joffré Maneli .....Specialized education
Johanne Gouskos.....Specialized education
Josée Desautels .....Specialized education
Karine Lamarre .....Specialized education
Mellissa Neveu.....Specialized education
Sophie Bilodeau .....Specialized education
Caroline Hudon.....Social work
Marianne Mercier .....Social work
Karine Plante .....Nursing
Stéphanie Lemay.....Nursing
Sylvia Sante .....Musicotherapy

The Félix-Hubert d'Hérelle corporation

3738, rue St-Hubert
Montreal (Quebec) CANADA
H2L 4A2

Telephone : (514) 844-4874
Telecopier : (514) 842-2991

Web site : www.herelle.org

E-mail : herelle@videotron.ca

Annexes

Care giving for people Living with HIV/AIDS

An opportunity For personal growth

BY FRANÇOISE MOQUIN**, INF., M.SC.**

Source :L'infirmière du Québec, novembre/décembre 1999

The quick transformation of the health system makes life difficult not only for the patient but also for the caregiver. To give us a glimmer of hope, the author shares her experiences at the Maison d'Hérelle, a community shelter located in Montreal, able to welcome 17 HIV/Aids affected individuals. She highlights our need, as caregivers, to learn to accept help, in order to be more in tune to the requirements of our clients, so as to better adapt to their needs.

The treatment of people living with aids has been substantially modified during the last years, especially since 1996. Indeed, due particularly to the new therapies that lengthen the life of those individuals, - some of them sometimes return to their workplace after regaining enough autonomy - residences like the Maison d'Hérelle must deal with new realities. Even as they continue offering palliative care to residents who require continuous day and night care, they must also receive an increasing numbers of clients afflicted by multiple related problems, such as, drug-addiction and homelessness.

Thus, while more than half of the nearly 200 individuals that have been welcomed by the Maison d'Hérelle[1] since it opened in 1990, have passed away during their stay, many others have been able to return to their own homes. These numbers emphasize the importance of accompaniment, as provided by our caregivers and the clerical, administrative, kitchen and maintenance staff. Organized following the model of a community-based organization the *Maison's* team operates according to the principle of shared responsibilities, carried out by different committees, such as: admissions, alternative health care, residents' needs, planning, medical attention, etc. The entire staff meets one afternoon every two weeks.

The health-care team is multi-disciplinary: its members come from different disciplines, such as nursing, special care counselling, social work. Many of them have completed their training through supplementary practice in massage-therapy (*shiatsu*), therapeutic touch, naturopathy, aromatherapy and herbal and phytology (herbal treatment).

Furthermore, some 175 volunteers, participating in accompaniment services in reception, kitchen and maintenance activities, greatly contribute , and are essential to the smooth operation of the Maison d'Hérelle.

Demanding and rewarding accompaniment

HOW DOES A MULTI-DISCIPLINARY TEAM OPERATE, WITH RESPECT TO HEALTH CARE AND SUPPORT RELATIONSHIPS, IN THE PRESENT CONTEXT of rapid changes that demand from health professionals

complete immersion in a continuous As a nurse who coordinates health care activities at the Maison d'Hérelle, I wish to bear witness to the fact that the bond established with the residents during this most difficult moment in their lives, turns out to be a unique opportunity for the caregivers to learn about themselves, and thus become capable of better understanding the patients.

Furthermore, the answer to the above question is a complex one, for the simple reason that we cannot always act in the same manner. We start by setting up a plan of action - the accompaniment program - agreed upon by each resident according to their individual needs. Then we look at the program as an experimental activity, where we express and discuss our individual points of view. Since opinions often differ, we try to reach a consensus. Needless to say, mistakes themselves are part of the experiment and the ensuing learning process. The following case history describes our accompaniment approach.

CONSENSUS BASED ACCOMPANIMENT

Individual B., HIV positive, has developed AIDS and also exhibits an AIDS-induced neurological problem. Although he was initially hospitalized, his present condition does not warrant further hospitalization. B. is spatially disoriented and confused, and walks only short distances on his toes, in mincing steps. His social isolation due to the absence of friends, his family living abroad, and his cramped apartment, do not permit his return home. With the assistance of the social worker B. was admitted to the Maison d'Hérelle, where we are involved in trying to come to his aid.

B.'s arrival - who loses his way to his room - provokes a strong reaction on the part of the other residents and of the whole team. To mark his way, we install placards bearing his name and giving directions to the main places where he has to go. With the support of volunteers and trainees, who are always available, we ensure a regular presence around B. He is slowly getting used to his new home; his walk has become more confident and he shows increasing degrees of autonomy.

Due to his marked improvement, B. wants to venture outside the Maison. Attuned to his needs, we usually manage to satisfy him, waiting until someone can accompany him. However, given the intensity of his need for freedom and the vastness of the Maison d'Hérelle, he sometimes disappears in spite of our watchfulness. Often, during these furtive outings, he tumbles in the streets and is brought back by the police. He has even come back with stitches and we were reprimanded by the hospital services, who entertained doubts as to our ability to take care of B.

The above situation triggers a lively discussion within the team in charge of B. We question B.'s safety and our own responsibility. Should we keep him? Might he not be better off in a more secure place where doors are kept locked? Finally we agree to keep him for another period, with the assistance of external resources able to provide companionship, such as the CSLC and the Maison Plein Coeur. First of all we explain to him what is happening and make it clear that he understands the dangers of suffering serious injuries during his lonely walks. We also share with him our anxiety: should anything happen to him, we would never forgive ourselves. We allow him to choose between the Maison d'Hérelle and another, more sheltered, residence. He decides to stay with us. Nowadays B. feels much better, to the point that he has tried to go back to his old job. His state of confusion has progressively decreased thanks to a balance between medication, herb treatment, massage therapy which he greatly appreciates, and also the attention and affection he receives from the staff members, and from a specific volunteer. When asked about his experience at the Maison, he answers mockingly that he was "crazy" at the beginning… To think that we had questioned the wisdom of keeping him at the Maison d'Hérelle!

The improvement in B.'s condition is a reflection of one of the different approaches we use at the Maison d'Hérelle. The well-being of the resident - who participated all the time in the decision-making process - has profited from the creativity of all the members of the team.

Moreover, we acted in unison, not hesitating to make use of external resources when needed. This forced us to accept the limits of our knowledge. Even if this type of procedure sometimes leads to situations without solution, we derive great satisfaction from working like this, with our hearts.

Accompaniment as a tool for growth

THE CONTEXT in which we have to accompany the residents in order for them to surmount a difficult stage in their existence, allows us to look again at our concept of attachment and detachment. Admittedly, we could always choose to work in such a way so as not to be affected emotionally. After all these years of rapport, should we not be capable of disassociating ourselves, of keeping a certain distance in order to avoid the pain of attachment? This question arises on a regular basis but, at the Maison d'Hérelle we have chosen to accept being affected by the persons that we accompany, like a mother who sees her children leave the family cocoon. It is not easy to witness the return of residents to their homes when their physical health has improved knowing that a great emotional frailty still remains., whose physical health has improved. But of whose great emotional frailty we are fully aware.

To illustrate the process of attachment and detachment as lived at the Maison d'Hérelle, I would like to draw a parallel with my own personal experience in my role as a mother of two daughters.

A PARALLEL WITH A PERSONAL EXPERIENCE

After many years spent as the "mother" within a family unit organized around them, I have felt my daughters growing

progressively detached from me, becoming more and more "independent". I found it difficult to see them fly with their own wings. I had the feeling of "losing" something; I feared losing the privileged place I had occupied in their lives, and also their love for me. At that time we talked all this over. I listened particularly to my oldest daughter as she voiced her desire to leave the family circle and to live on her own. She felt she did not belong any longer in this family of four, and vented her fears and anger. As for myself, I shared my own feelings, my difficulty accepting that she had already reached that stage in her life, my sense of loss, and my anxiety regarding our future relationship after her departure.

Afterwards we agreed to help each other by sharing our feelings as equals. Now we share our experiences like two adults, and our relationship remains strong, even if we spend less time together. And our love for each other remains unchanged.

As in this mother-daughter experience, interventions at the Maison d'Hérelle are fraught with love and we become intensively involved on an emotional level. Many times, residents have touched me deeply, there being something between us that brought us closer. I remember especially M. whom I was accompanying during his last moments. When I allowed myself to tell him that I loved him, tearfully and with a lump in my throat, he answered that he also loved me. M. and also others have been crucial in making me realize that in my heart there was still room for one more love, and that it would endure in spite of separation or death.

Accompaniment, as experienced at the Maison d'Hérelle provides a unique opportunity to think about ourselves, about our own lives, and our ability to evolve. Through them we learn to better understand our reactions, especially in the face of death. At the very beginning I used to feel ill at ease when having to speak of such a serious topic with someone of my own age. I had a bit of difficulty in finding the proper words and I was afraid to blunder. It happened, for example, that I talked to a resident about the flowers that promised to be so beautiful in the summer. When he answered that he would not be of this world by that time, I blushed violently and felt embarrassed. As time passed, however, I realized that I was the only one disturbed by this type of comment that only revealed my own shortcomings. I learned to identify the things that frightened me and to accept my mistakes. I also found out that the residents themselves found it equally difficult to discuss death. Thus, together, we learned to talk about it and I let intuition show me the suitable moment to do so.

Besides, the approach of death gives the present a completely different perspective. We often project ourselves onto the future, thereby overlooking the richness of the present moment. One day, L. said to me: "I sense that you are disconnected, not totally with me at this moment." I denied it from sheer pride, but I was actually worried, and L. perceived it very well. His comment forced me to get things into focus again; it took me a couple of instants to establish my order of priorities, and to become attuned to him again.

Learning to accept help in order to be able to help others

OUR DIVERSE BACKGROUNDS as caregivers make us wish to help others. Is this deep desire to make others feel better, not an expression of our love for the human being? The practice of our nursing profession teaches us that helping means taking care of the fundamental needs of individuals, considered as a whole, that is to say in their physical, psychological, social, and spiritual qualities. At the Maison d'Hérelle we constantly put this concept into practice. However, in the middle of this flood of changes, we also learn to take care of ourselves. The question is how to do it and how to set our priorities.

At one point, we - the members of the team - were under the impression that we were working in a "five star hotel", where services had to be provided immediately and with precision. The demands for services that residents could have satisfied by themselves, made our task disheartening and exhausting. We then asked ourselves: are they abusing us? Our time? Our kindness? As to the residents, they insisted that we did not take enough care of them, that we did not respond to their requirements promptly enough. There were ill-feelings on both sides and each side had its own share of responsibility.

Thus, staff and residents met and, to avoid confrontations, we decided to approach the situation with humor. This exchange of views allowed us to discover that we often skirted around the real needs which, as a result, were never satisfied.

Thus, we understood that the continuous demand by a resident for a glass of water, or for ice cream, or whatever, concealed a very real need for attention. Because of his declining health, he needed a reassuring presence to appease his anguish. Therefore he agreed to fetch his glass of water himself, but demanded clearly from staff and volunteers that someone be always at his side so that he could voice his fears. The result was that, as we defined our personal and collective duties, we allowed this resident to determine and express what he exactly wanted from us.

All these years of experience have also enabled us to notice that, as caregivers, we experienced

difficulty in taking time for our own needs, in taking care of ourselves, and in accepting help from others. In our personal and professional life, however, we are constantly encouraged to learn and practice these three laws in order to avoid stress, fatigue and exhaustion. Indeed, to always give to others without ever giving to ourselves, is as much a cause of imbalance as when one only think of oneself and never of others. This is an easily forgotten lesson when we are working against the clock! In any case, exceeding our limits - skipping a meal, for instance because we are short of staff - does not help matters.

At the Maison d'Hérelle we have never ceased to adapt our concept of work and the necessary conditions to offer a first class accompaniment service. These conditions include the right to receive aid. In this respect, those who are there to take care of the clients - staff, volunteers and trainees - can be treated by a massage therapist, (a service previously reserved exclusively to the residents), without feeling guilty of being pampered themselves. If one of us needs it, we support each other collectively, so that he or she, can have access to this type of therapy.

Hence, by opening the door to mutual aid, we reinforce the bond between the members of the team. We have observed, moreover, that the fact that each of us tries to acquire a better understanding of our own essence which leads to a state of well-being that is perceived and recognized by both the staff and the residents. As we learn to know ourselves, we come to regard our limits as natural, indeed, as central to our opening up to our fellow human beings.

[1] The Maison d'Hérelle is administered by Corporation Félix-Hubert d'Hérelle, a non profit organisation financed by the Ministry of Health and Social Services, Centraide, and through private donations.

Acknowledgements

Françoise Moquin wishes to thank Anne, Carole, Denyse, Pierrette et Mireille, who helped through their comments and the text revision, hence allowing the author to further pursue her own growth.
L'infirmière du Québec would like to thank the Maison d'Hérelle's residents who also contributed through their photo sessions.

Françoise Moquin, a licensed nurse, is the Health Services coordinator at the Maison d'Hérelle. She has a master degree in Community Health Services. Along with Michèle Blanchard, executive director, she co-authored a book called "Êtres aux Passages de la Vie".