

**INTÉGRATION**  
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MESSAGE FROM THE CHAIRPERSON

*Residential resources*

**A living environment first and foremost**

Much has been written and said on the topic of residential and long-term care facilities, family-type or intermediate resources and other such centres in recent months. A succession of unfortunate events in some of these establishments have been front-page news in Québec, with the result that Health and Social Services Minister Philippe Couillard decided to launch an investigation into events that occurred at the Saint-Charles-Borromée hospital, and ordered an inspection of several other care facilities where problems were reported.

Although many residential care facilities are recognized for the quality of their programs and services, recent events have focused on the problems that other centres or homes experience. Unfortunately, these occurrences are only the latest in a string of events that have been reported over the years. The Office des personnes handicapées du Québec (OPHQ) is extremely concerned about the quality of the services provided to persons with disabilities in all types of residential care facilities, which is why we have chosen to focus on this topic in this issue of *L'intégration*.

Whether a person enters a residential facility due to aging and a subsequent loss of autonomy or because he or she is disabled, his or her basic needs are the same: food, lodging, care and assistance. We must keep in mind that for many people with severe disabilities, whether physical, intellectual or psychological, such facilities are their only option when it comes to adequately fulfilling these needs. However, it would seem that the emphasis is too often placed solely on the caregiving aspect of these facilities, whereas they are actually a living environment for their residents.

People with severe disabilities are, in a sense, prisoners of their residential environment, which means that when there are organizational difficulties or situations arising from insufficient know-how on the part of the staff, a lack of resources or just plain attitude problems, they are the ones who bear the brunt--which is unacceptable.

Neither should we forget that these homes or centres should resemble their residents' natural living environment as closely as possible. We may well worry, in some cases, about the situation of persons with disabilities who, in addition to requiring specific care, seek an environment that fulfils their aspirations in terms of socializing, recreational activities, entertainment, and so forth. If we take this reflection one step further, we might even wonder how many of these people would perhaps have been able to remain in their own homes if, for example, they had had access to proper home-care services, or if the Dwelling

Adaptation program had been able to respond to their needs within a reasonable period.

In the OPHQ's opinion, the first choice should always be the natural living environment, provided the person has access to the necessary resources. When this is no longer possible, it is essential that the person enter a residential facility that resembles his or her own home environment. We should be glad that the motivation triggered by the concept of "living environment" has spawned a number of ideas and projects in various regions of Québec. In fact, the OPHQ is supporting different initiatives by participating in regional issues tables on social and community housing, sitting on committees to develop alternative resources and contributing to innovative accommodation projects.

Since it is responsible for ensuring the coordination of the services offered to persons with disabilities, informing and advising them, and promoting their interests, the OPHQ would like to see the quality of services and the well-being of the residents in all types of residential facilities guaranteed through systematic monitoring. Also, the OPHQ believes that it is vital that everyone be made aware of the importance of doing their work in a spirit of dignity and respect of the residents of care facilities.

**By Norbert Rodrigue**

## INTERVIEW

### **Martin Deschamps: a true rock 'n' roller at heart!**

After taking a well-deserved break last year, Martin Deschamps has once again agreed to act as the spokesperson for Québec's Week of the Disabled, which takes place each year from June 1 to 7. Not only did he take advantage of this hiatus to record a new album, but he also produced another work of art: a baby daughter. Little Lou was born in 2003... during Québec's Week of the Disabled, if you please!

With *Le Désert*, his third album in four years, Martin's career has reached new heights, and he has become a household name on the rock music scene. Obviously, he is enormously talented, but without perseverance and determination, would he have succeeded? Performances, tours, promoting his music on TV and radio... it would seem that Martin's life is constantly bustling with activity. Not one to rest on his laurels, Martin likes things to shake, rattle and roll; on stage, he is in his element.

This charming, warm-hearted rocker also takes the time to get involved in causes he believes in, such as helping sick children by donating part of the proceeds from the sales of his record "*Comme je suis*" to the Sainte-Justine hospital, and supporting persons with disabilities through his work as spokesperson for Québec's Week of the Disabled in 2002 and 2004. Not only is his heart warm, it's also big!

Last year, in an interview with Michel Tassé published in *La Voix de l'Est*, he confided: "Now, people look at me with admiration in their eyes, instead of pity and discouragement. I've written some good songs since the beginning of my career, but having succeeded in changing the way people see me is my biggest hit." Despite his busy schedule, he kindly agreed to answer a few of our questions.

***L'intégration: Martin Deschamps, how did you become interested in singing and songwriting?***

Martin Deschamps: When I was young, I loved music, especially African and Latin American music and music with percussion. It's funny, because my parents had a record collection, and I always chose the same records, even though I was too young to be able to read the album covers! Later on, around age 11, I received a drum set as a gift, and that's when I discovered my musical bent. After that, I had to switch instruments because one of my friends already played drums. I started composing with a bass guitar while listening to my favourite groups--the Rolling Stones, the Beatles, Deep Purple, Led Zeppelin. I've lived for music ever since I was small.

**Did you ever take music lessons?**

I took drum lessons for three or four months, but I had to teach myself bass guitar. I'm the only person who knows how to play with two fingers and half an arm!

**Speaking of which, has your physical impairment been an obstacle during your career?**

At certain times, but it's also been an asset because, given that I'm different, people remembered me once I'd met them. When you're disabled, you definitely have greater obstacles to overcome, but you develop ways of doing so. You end up with plenty of guts because you have to deal with adversity more often than people who are lucky enough to have all their limbs. I consider myself fortunate to have had the guts to achieve my goals and do what I want in life.

For sure, I knocked at a lot of doors and got plenty of them slammed in my face. Was it because of my disability? Maybe, but no one ever told me so. I preferred not to dwell on that and just keep on knocking until I met André Gagné, my agent and friend. He keeps my career running smoothly and I'm very thankful for that.

**Everyone knows that appearance is important in the world of the performing arts and that perfect bodies are worshipped. How do you cope with this reality?**

I think I have a certain look that's maybe not within the norm, but it's unique and gives added value to the product Martin Deschamps. I try to play down the situation by showing people that I'm in this business because it's my passion, because I love music and I like human contact. Those who understand my philosophy and the way I see life get something out of it, I think.

**Do you consider yourself disabled?**

Of course! If I didn't grab my crutches first thing when I get out of bed in the morning, I'd fall flat on my face! Let me make one thing very clear: I'm a person with a disability, but I don't set myself any limits. I try to ensure that my difference doesn't compromise my projects and dreams.

**What motivated you to accept the position as spokesperson for Québec's Week of the Disabled? Is there a particular message you'd like to transmit?**

The Week of the Disabled definitely informs people and makes them more aware. My personal aim is to play down the situation. What I mean by that is that we should accept people with disabilities as they are, without dramatizing their situation. I think it's important to have a positive attitude toward life, whether you're disabled or not. That's where I think I can help out.

I'd like people to have feelers, to be attentive to those around them, to share. People who are comfortable with themselves, who are healthy, can, like me, make a physical, mental, verbal or even musical contribution. It's important to keep your feelers out and realize that if you do good around you, life will reward you and you'll be a winner.

**Martin Deschamps, what is your proudest achievement in life?**

Until recently, I would have said my albums, but now I'd have to say my daughter. She's beautiful and she brings me so much happiness.

**By Micheline Thibault**

**FOCUS**

*Residential resources*

**Living in a residential care facility**

People who live in residential care facilities generally do so because of their physical or mental state. Although various types of residential resources exist, residential and long-term care centres (RLTCC) are sometimes the only available option. The clientele of RLTCCs, although largely made up of elderly persons, also includes younger people with disabilities who have pressing needs.

All these people have so-called basic needs that they are unable to meet themselves and which require the relatively constant presence of various resource people. Some of these needs include lodging itself, food, medical treatment, personal hygiene and assistance getting around. But there's more. These residents may also require civic support services, such as help managing their budget, filling out forms or simply opening and sorting through their mail.

**Observations**

Regardless of the type of centre they live in and independently of the quality and quantity of the care provided to them, everyone in a residential environment

is entitled to feel “at home”, in other words, to benefit from an environment that satisfies their need for privacy and their aspirations in terms of recreation, entertainment and social activities.

A current analysis of life in a residential care centre highlights numerous difficulties which mean that the residents do not always receive all the services to which they are entitled. Questioned in this regard, Céline Marchand, intervention consultant with the Direction de la recherche, du développement et des programmes of the OPHQ, confirms that several problems have been raised in the past few years, by rights advocacy organizations, families and various resource people working in the residential environment. “The problems reported relate, in varying degrees, to most sectors of activity and management of residential care facilities,” explains Ms Marchand, “and all of them deserve our attention.” In terms of human resources, some problems can be ascribed to a lack of know-how due to insufficient staff training, inadequate professional support or a lack of sensitization on the part of the administration to social participation and inclusion objectives or the principle of empowerment. In addition, staff shortages mean that the attendants are often overworked, which sometimes results in situations of negligence and is also a source of concern and complaints. Problems can also stem from inadequate staffing due to a vague description of the qualifications required and shortcomings in the assessment of the organization’s requirements. Complaints have also been filed in relation to the ethical aspect of physical and chemical restraint and isolation measures.

### **Necessary improvements**

Given the seriousness of the situation in certain residential facilities, corrective measures should be envisaged, such as the implementation of systematic mechanisms for monitoring service quality, including the enforcement of a zero-tolerance policy with regard to clientele abuse and regular, impromptu inspections of the centres. Other solutions include the development of user manuals for employees of residential centres, drafted along the lines of recognized guides to professional practice, and the preparation of codes of ethics, service statements to users or charters of rights. For the benefit of residents, their families and friends and the community in general, the residential environment must be open to the outside world and, in the case of people who are isolated and more vulnerable, create a rights advocacy system.

As concerns staff training, better basic education, access to professional development and periodic evaluation are required. Moreover, staff members should receive more effective supervision and professional support and have their work recognized by society. In their report concerning the situation at Saint-Charles-Borromée hospital, Ms Louise Chouinard-Desrosiers and Mr Jean-Jacques Camera refer to the importance for the next director of “making it a priority to set up a process allowing for more effective definition and control of all aspects of the relationship with and supervision of the work teams on the units.”<sup>1</sup>

“Our observations tend to show that the best solutions depend on how the residential environment is perceived,” says Céline Marchand. Indeed--solely as

a place where care is given, or as a natural living environment? The evidence seems to show that if the residential centre is considered first and foremost as a living environment, services are organized differently, with the emphasis placed more on the well-being of the residents and their needs as a whole.

Clearly, the quality of the services provided to persons with disabilities by the residential staff is an issue of great concern, as is the implementation of systematic mechanisms for monitoring the quality of the overall services provided in these facilities. “Regardless of the type institution that provides them, in order for the services offered to disabled persons to be truly effective, they must first and foremost target personal dignity,” concludes Céline Marchand.

**By Michael Watkins**

<sup>1</sup> Report concerning the situation at Saint-Charles-Borromée hospital, December 5, 2003, p.8. [Free translation]

## Types of residential resources by establishment<sup>1</sup>

Types of resources		Description
Institutional	Reception centre, RLTC	In this type of establishment, residents receive all their services in-house.
	Group home	Intended mainly for children, this small-scale resource belongs to the establishment which provides services directly.
Non-institutional	Specialized resource	A place where residents live together and receive around-the-clock assistance from the staff of the establishment.
	Intermediate resource (IR)	This private resource (for profit or non-profit) offers accommodation, assistance and, occasionally, rehabilitation services according to a contract binding it to the establishment, although the latter is responsible for the clientele. Even though IR generally resemble family-type resources, some larger ones are housed in pavilions.
	Family-type resource	Foster families (for children) and adult foster homes are bound by contract with an establishment to provide accommodation, meals and assistance to the persons entrusted thereto.

<sup>1</sup> "Establishment" generally refers to a residential and long-term care facility or a rehabilitation centre.

### FOCUS

#### *Residential resources*

#### **A more natural living environment**

In the wake of a research and reflection process conducted over a number of years, the Québec division of the Multiple Sclerosis Society of Canada (MSSC) published, in August 2000, a white paper on meeting the challenge of ensuring better living conditions for adults with severe physical disabilities who are no longer able to remain in their homes. *L'intégration* spoke with Ms Magali Plante, director of client services and social action with the Québec division of the MSSC.

“Not everyone with multiple sclerosis (MS) has to resign themselves to leaving their home one day,” explains Magali Plante. “Their functional limitations caused by the progression of the disease do not become sufficiently severe for that.” Indeed, it would appear that in many situations, the support provided by friends and family, natural caregivers, the CLSC or a social-economy organization offsets these limitations, thereby allowing the person to remain in his or her home, which is precisely the approach the MSSC advocates, maintaining that it costs less to keep a person in his or her natural living environment than to place them in an institution.

The MSSC feels that a person should consider leaving his or her home only as a last resort, but when this happens, people between the ages of 18 and 60 with MS find themselves mainly surrounded by senior citizens. It should be pointed out that residential and long-term care centres were originally intended for the latter category of clientele. Since adults with MS are often no older than 40 when they are institutionalized, numerous problems related to cohabitation of the two age groups are raised. The fact is that despite their disease, most of these people are still able to assume their social responsibilities and participate actively in community life, and the same often applies to other adults in care facilities, whether they have quadriplegia, spina bifida, muscular dystrophy or another degenerative disease. “Since we can expect a substantial increase in requests for institutional placement due to the aging population, the quality of the services residential and long-term care centres will be able to provide in future is of some concern,” explains the director.

### **Unsatisfied needs**

According to the Régie de l'assurance maladie du Québec, 11.1%<sup>1</sup> of all adults living in residential care centres are under 65. In general, they have a number of unsatisfied needs that can be divided into three categories: physical, psychological and emotional, and social, recreational and cultural.

With regard to physical needs, scheduling inflexibility and overworked staff are often a source of problems related to personal hygiene, bathing frequency and restrictions on the time spent out of bed. This situation is the same for all residents, adults and seniors alike. “Another example is that the ambient temperature in these facilities is often high because the elderly tend to feel the cold more, but this greatly affects the quality of life of people with MS, who have trouble enduring heat,” says Ms Plante regretfully.

From a psychological and emotional standpoint, the lack of privacy and places to get together with family and friends is just as difficult for seniors as it is for adults. However, cohabitation between the two age groups becomes even more complex when an adult must share a room with elderly persons who are confused or suffer from dementia. Some adults living in residential care facilities recount situations where seniors wander from room to room, or complain about the cries and constant noises made by patients suffering from psychological disorders, which obviously affects their sense of privacy and well-being. Several other factors can contribute to the deterioration of the condition of adults in long-term care, including removal from their natural living environment, fear of

losing their identity, the lack of accommodation of spousal relationships and the lack of acknowledgement of their potential.

In terms of social activities, recreation and culture, some care facilities control their organization and services so rigidly that it is impossible to plan outings with volunteers. An example of this is a resident in her 40s, who complained that she was forced to go to bed at seven o'clock because, she was told, that was lights-out time for everyone else on her floor.

The least that can be said is that in these conditions, it is difficult to maintain a social life, especially since the programs and activities prepared with the majority of residents in mind do not always correspond to the tastes and values of people in their 20s, 30s or 40s, who are more interested in shopping, theatre, movies and other similar activities. It is no wonder that many adults have a tendency to withdraw and become isolated. "It's a shame to note that some of our members are only allowed out of bed from two to six times a week for three hours at a time, and that they're forced to spend the rest of the day staring at the walls or watching TV," deplores Magali Plante, who would like to see more flexibility with regard to adult residents and support granted to family, friends and volunteers who want to get involved.

### **A different approach**

The MSSC is one of many groups demanding the development of a residential resource network that is better adapted to the needs of adults who are no longer able to remain in their homes. Different ideas have been put forward, such as a network of residential and long-term care facilities devoted chiefly to a younger clientele, or smaller-scale residential projects known as "substitute living environments" or "alternative accommodation." Since such changes cannot be made overnight, the transformation must be gradual, but everyone realizes that the reorganization of the services offered to adults is a pressing need.

The MSSC has suggested other ways of reorganizing services, such as reserving a floor or a wing of a residential and long-term care facility for the accommodation of younger residents, or partnering with non-institutional resources to create living environments with 24/7 staffing. In this respect, a few projects should be mentioned. First, thanks to a grant allowing it to devote an entire wing to adults with MS between the ages of 50 and 60, and another to younger residents with the disease, the Lajemmerais residence, affiliated with the CHSLD du Littoral in Varennes, offers an environment where residents can live at their own pace. The staff readily participates in activities, outings are organized and all types of innovative programs are proposed to respond to the needs of young adults.

Elsewhere, as a result of close collaboration between the Horace-Boivin residence, Granby Hospital, the Haute-Yamaska CLSC and the Haute-Yamaska chapter of the MSSC, eight adults were housed in the Ulysse Gauthier pavilion in August 2000. All the residents and partners agree that this project is an unqualified success thanks to a concerted approach that focuses on the individual and his or her needs. The Horace-Boivin residence managed

to alleviate the strain on institutional resources by encouraging strategic partnerships between institutional, private and community facilities, while creating a living environment that is stimulating and open to the community.

Other examples include the specialized service units developed in the 1970s by the Centre de réadaptation Lucie-Bruneau. These are apartment groups supervised around the clock by Centre staff. The main advantage of this type of facility is that it allows residents to continue living independently and participate in community life while still having access to qualified personnel. These are only a few examples of successful initiatives, but their common denominator is a genuine concern for offering residents an environment suited to their needs. Sometimes very little effort is required. For example, in one facility in L'Annonciation, residents with MS are housed in a prettily decorated wing where the temperature is controlled.

“Although these projects pave the way for other similar initiatives, they are still few and far between. The demand far exceeds the available space in these facilities, be they restructured long-term care facilities or alternative accommodation,” states Magali Plante.

The MSSC realizes that the budgetary restrictions Québec is currently facing do not make things any easier. In its opinion, the situation calls for self-help, maximum use of existing resources, and closer ties with outside resources. “Improving the living conditions of people with MS and other chronic degenerative diseases requires a reorganization of accommodation facilities, human resources and services so that these adults can have access to a living environment that is more natural, stimulating and suited to their specific needs,” concludes Magali Plante. **MW**

<sup>1</sup> Source: Régie de l'assurance maladie du Québec, MSSS data.

## PROFILE

### ***When I was an animal*** **Beautiful chemistry!**

Geneviève and Pascale share the stage of a small theatre nestled in the heart of Montréal. These two women, though very different, are equally moving in their chemistry. The enjoyment they obviously derive from performing together is contagious, and the audience quickly falls under their spell. Geneviève Morin-Dupont, amateur actress, has an intellectual impairment and has been working with the *Les Muses*<sup>1</sup> performing arts centre for the past two years, while Pascale St-Jean is a professional actress.

*Quand j'étais un animal (manuel de taxidermie)* is a dramatic work made up of improvisation, conversations, images and sounds. The concept of taxidermy is used as a creative pretext to portray contrasts, oppositions and similarities, such as immortality or death masquerading as life; the world of appearances, which is a genuine cult in the land of the living; and a blend of reality and

fantasy, the body as envelope stereotyped, transformed, mutilated. All of this is presented with humour but in such a way as to prompt reflection.

Catherine Bourgeois, a young director, met Geneviève at *Les Muses*. With her partner, Amélie Dumoulin, she was in the thick of creating a theatrical work, and the idea of including an actor with an intellectual impairment appealed to her. "As a director, I wanted to open theatre up to other possibilities and people other than well-known actresses," explains Catherine. And indeed, Joe, Jack & John, the company they founded in October 2003, stands out precisely because of the participation of non-actors or people with certain differences in the creative process, for the purpose of "creating an effect of strangeness that is essential to reflection and poetry." This inclusion of a person with an intellectual impairment from the beginning to the end of a professional company's creative process was a first in Québec. From May 2003 until to the performance of the play in January 2004, Catherine, Amélie, Geneviève and Pascale met twice a week in order to lay the groundwork for this creation, which was warmly received by a seasoned theatre-going audience.

### **Geneviève's background**

Geneviève is 22 years old. In 1994, she got her start in front of the cameras with a role in the film *Un billet de loterie*, a France-Québec coproduction. The following year, she joined an amateur theatre troupe called *Notre théâtre*, made up of persons with disabilities. Two years ago, she began attending *Les Muses*, where she took drama classes with professional teachers. "I acted in *Ailleurs*, at the Centre de la culture Mercier, and that's where Catherine and Amélie saw me for the first time," says Geneviève.

### **The creative process**

Geneviève was an important part of the creative process, from beginning to end, playing multiple roles as author, creator and actress. "We didn't force her to play a specific role or learn specific lines," explains Catherine. "We drew directly on her universe and imagination to create the characters. Geneviève provided the raw material, just like Pascale, the other actress, Amélie and I did."

Unlike what has previously been done with intellectually impaired individuals in a theatrical context, Geneviève does not play herself. "She doesn't play a 22-year-old woman with Down's syndrome," explains the director. "She plays roles from her imagination. We showcase her as an actress in her own right, not as a theatrical object."

Improvisation doesn't seem to have been a problem for Geneviève who, when asked about it, is obviously sincere when she replies cheerfully, "I love improvising!" However, she found it difficult to memorize her lines, especially since she had so many. "I had trouble learning my lines by heart. Amélie and Catherine called me to practice on the phone, but I soon realized that I was capable," she says proudly.

Geneviève fit in with the others easily. "It went smoothly because Geneviève is such a loving person," smiles Catherine. "She took to us right away." All that had to be done was give clear instructions and set limits. "She's like a

mischievous child, she knows how to manipulate those around her,” says Catherine, admitting that even she was taken it at first. As for the public’s reception of the play, Catherine had a few worries that were quickly dissipated after the first performances. “I was scared, I felt I was taking a risk ... but the connection between Geneviève and Pascale worked a kind of magic. The audience was in awe.” Thanks to word of mouth, the play quickly sold out.

### **And now that it’s over?**

“I would definitely do it again, but over a longer period, because it’s important to take the time to assimilate and incorporate the creative aspect,” explains Catherine Bourgeois. “More and more, I realize how much Geneviève enriched the work and set it apart from the countless others that are presented onstage in Montréal. It was a performance that promised something new, a new way of seeing things, and it delivered on that promise.” She says her perceptions have changed thanks to working with Geneviève. She is now more open to differences and is more aware of the person behind the disability, behind the appearance.

Although there were nine performances of the play in January, Geneviève too would do it again in an instant. “I’m going to miss Amélie, Catherine and Pascale. I’d like to work with them again and I wish them good luck!” As an apprentice with the Union des artistes, she even received a fee for her work as an actress. “It’s the first time I’ve ever been paid for acting!” exclaims Geneviève.

**By Micheline Thibault**

<sup>1</sup> The Centre d’arts et de loisirs Les Muses offers drama and improvisation workshops to persons with intellectual impairments to stimulate their enjoyment in creating, expressing themselves and acquiring self-confidence.

*Note: Geneviève’s wish came true, because L’intégration has learned that the play was performed again on March 16 on the occasion of Intellectual Impairment Week in Québec.*

## OVERVIEW

### **A digital library**

In fall 2003, the Canadian National Institute for the Blind (CNIB) launched its digital library, which boasts over 10 000 audio, text and braille titles available online for immediate reading. Users can listen to talking books on their computer, and access newspapers, magazines and databases. The library also offers the Children’s Discovery Portal, the first of its kind, which enables blind children to play games, participate in surveys, obtain homework help and chat with other children. You can visit the library and the portal at [www.cnib.ca/library](http://www.cnib.ca/library)

### **Compassionate care benefits**

As of January 4, compassionate care benefits may be paid up to a maximum of 6 weeks to a person who is eligible for Employment Insurance and who has to be absent from work to provide care or support to a gravely ill family member at risk of dying within six months. More information can be obtained by calling, toll-free, 1 (800) 206-6352, or by consulting the HRSDC Web site at [http://www.hrsdc.gc.ca/en/ei/types/compassionate\\_care.shtml](http://www.hrsdc.gc.ca/en/ei/types/compassionate_care.shtml)

### **Time management**

According to a survey conducted in France last summer for Handicap International, a non-profit organization, the parents of disabled children spend two and a half times more time looking after their child (6 hours and 25 minutes per day, as compared with 2 hours and 36 minutes per day for a child without disabilities). The families polled noticed a significant increase in the time devoted to parental duties to the detriment of household tasks or leisure time (78%). In addition, 44% of the mothers surveyed scaled back their working hours due to their child's disabilities, and 20% stopped working altogether.

The survey also shows that the level of dissatisfaction and concern in these families is on the rise. Whereas only 12% of them say they are satisfied with their situation, 44% of them have financial difficulties due to their child's disabilities. The French magazine *Décllic* reported on some of the survey results in its December 2003 issue. To obtain a copy of the full survey report, write to [servicepresse@handicap-international.org](mailto:servicepresse@handicap-international.org).

### **A unique initiative**

The concern of a number of parents about what their intellectually impaired children would do after graduating from school has resulted in a unique undertaking. Since the youngsters learned to make decorations with dried flowers in school, their parents decided to set up a workshop-boutique, with the help of *Action Chaleurs*, an association for persons with disabilities in the Baie des Chaleurs area, to allow their children to put their skills to good use. After much work and the collaboration of many partners, including the Office des personnes handicapées du Québec, the Atelier Amitié Déc'art opened its doors a few months ago. This pilot project will be assessed a year from now. For the moment, three young girls are participating in this experiment, and a supervisor was hired as well. For more information, please contact Bernard Babin at (418) 534-4543.

### **Events**

On **May 6 and 7**, the symposium *Défi loisir pour les personnes handicapées ou en perte d'autonomie vers la participation sociale* will be held at the Université du Québec in Trois-Rivières. This symposium, under the honorary chairmanship of Norbert Rodrigue, OPHQ chairman, aims to bring together representatives of the recreational community who work with persons who are disabled or losing their autonomy, for dialogue and reflection on the event's three themes: enhancing professional intervention and expertise development, developing

new practices and increasing partnership. For more information or to register, please call the Association québécoise pour le loisir des personnes handicapées at (514) 252-3144.

From **May 10 to 14**, the 72nd Congress of the Association canadienne-française pour l'avancement des sciences (ACFAS) will take place at the Université du Québec in Montréal. This year's theme is *La société des savoirs* (the knowledge-based society). As part of this event, the OPHQ will be presenting a symposium, in conjunction with the Institut de la statistique du Québec, on Thursday May 13, focusing on the social inclusion of persons with disabilities in Québec 25 years after the adoption of the *Act to secure the handicapped in the exercise of their rights*. Several experts in the area will be in hand. In addition, a publication entitled *L'incapacité dans les familles québécoises: composition et conditions de vie des familles, santé et bien-être des proches* will be unveiled. The day will conclude with a roundtable discussion led by Norbert Rodrigue, OPHQ chairman. To consult the list of seminars or to register, visit the ACFAS Web site at [www.acfas.ca/congres](http://www.acfas.ca/congres) or call (514) 849-0045.

On **May 27, 28 and 29**, the Association du Québec pour l'intégration sociale (AQIS) will hold its 23rd annual congress in Saint-Georges de Beauce, with Marc Dutil, president of the Groupe Canam Manac, as honorary chairman and *Ma contribution... un héritage* (my contribution... a legacy) as this year's theme. Various workshops will be offered, enabling participants to mingle, discuss and learn about new developments in the field of intellectual impairment. For more information or to register, call the AQIS at (514) 725-7245.

The exhibition *1, rue des Apparences* is presented in Sherbrooke until **June 6**. Produced in conjunction with the OPHQ, this exhibition was on display for over a year at the Musée de la civilisation in Québec City, and then began travelling throughout the province. Last year, it was shown in Sept-Îles. You can visit *1, rue des Apparences* at the Complexe Saint-Vincent-de-Paul, 300, King Street East in Sherbrooke.

### **New publications**

Most of the publications featured in this column can be borrowed from our Documentation Centre (1 888 264-2362).

Under the supervision of Yves Vaillancourt, François Aubry and Christian Jetté, the Presses de l'Université du Québec recently published a work entitled *L'économie sociale dans les services à domicile*, in which the authors feature research findings on the development of the home-care sector and, more specifically, the various forms of regulation used within home-care firms. The study identifies the main challenges stakeholders will have to meet in the development of this sector in the coming years. Available in bookstores, this book can also be ordered directly through the Web site of the Presses de l'Université du Québec at [www.puq.quebec.ca](http://www.puq.quebec.ca)

The Regroupement de parents de personnes ayant une déficience intellectuelle de Montréal, an association that brings together parents of children with an

intellectual impairment, has re-edited its series of brochures on special-needs schooling. This series of nine brochures comes in a attractive kit. The content has been updated and a brochure featuring information on the school-active life transition program has been added to the series. For more information or to obtain these brochures, consult the association's Web site at [www.rppadim.com](http://www.rppadim.com) or call (514) 255-3064.

*If you are organizing an event, publishing a document, or have information on a new organization that is active in the field of social inclusion, and would like our readers to know about it, contact us by telephone at 1 800 567-1465 (1477 by teletype), or by e-mail at [integration@ophq.gouv.qc.ca](mailto:integration@ophq.gouv.qc.ca)*

## POINT OF INTEREST

### **Person with disability seeks apartment ...**

There is a severe housing crisis in Québec. For the past few years, the population has had to cope with a housing shortage, and the situation is worse in large urban centres. Imagine, in such a context, how hard it is for persons with disabilities to find accommodation suited to their needs!

Trying to find adapted housing can be a real headache for persons with disabilities and their family and friends. Every year, several people contact the OPHQ for help and to learn about the resources available to them--for example, a disabled student who is leaving her home town to study at a CEGEP, a mother who has just learned that her daughter, a young adult with autism, has to move to another residential facility and is not satisfied with the change, or a lady with a motor impairment who lives in low-rental housing and whose apartment requires adaptations. When such situations crop up, it is important to clearly identify the needs of the person and the services he or she receives in terms of the housing problem in question. For example, the availability of the technical aids required and of home-care services can make a difference in the type of residential resources sought.

Various programs, measures and resources are available to meet housing-related needs, including the Rent Supplement program for low-income families and the Housing Allowance program for persons aged 55 and over. Other people may be eligible for low-rental housing with the necessary adaptations. The Dwelling Adaptation program mentioned earlier in this newsletter helps subsidize the cost of making the necessary modifications to the homes of persons with disabilities, whether they are owners or tenants.

Some regions have launched initiatives to inventory the adapted housing available in certain communities, thereby making the search for housing easier. Also, residential services offering additional support and supervision are available as part of the health and social services network, in the form of family-type resources (foster families) and intermediate resources.

The housing problem remains a significant one for persons with disabilities and is frequently due to insufficient funding, as we can see from examples such as

the waiting list for the Dwelling Adaptation program. The assistance granted to each individual to provide a solution to his or her problem must be based on collective development initiatives, to ensure that a wide variety of resources are available.

The OPHQ can help people experiencing housing-related problems to identify their needs and, thanks to its information base on the resources available in each region, refer them to the appropriate organizations.

**By Jean Dupont**

## LITERATURE REVIEW

### **Residential resources**

DORVIL, Henri; MORIN, Paul; ROBERT, Dominique. *Le logement comme facteur d'intégration sociale pour les personnes classées malades mentales et les personnes classées déficientes intellectuelles*. Final report. Montréal, QC: GRASP, Université de Montréal, 2001. (M6071)

With the advent of deinstitutionalization, several types of residential models have appeared. This study attempts to show that the type of living environment chosen can have a beneficial impact on the functional abilities, social inclusion and quality of life of persons with mental health problems or intellectual impairments. It also looks at the similarities and differences in the housing needs of both clientele.

THOMAS, Daniel; SYLVAIN, Louise. *Les besoins et la satisfaction en matière de logement des personnes ayant une incapacité liée à la mobilité*. Rouyn-Noranda, QC: Office des personnes handicapées du Québec, Conseil régional de développement de l'Abitibi-Témiscamingue, 2002, 129 p. (M6608)

This study begins with an overview of the housing programs and services offered in Québec to persons with motor impairments. It goes on to describe the needs and satisfaction level of these people in terms of the dwelling adaptation services currently available.

Multiple Sclerosis Society of Canada. Québec Division. *Adequate Living Conditions for Adults with Multiple Sclerosis Residing in Long-Term Care Facilities: A Challenge to be Met... Without Delay*. Montréal, QC: Multiple Sclerosis Society of Canada, 2000, 17 p. (A8599)

This white paper focuses on the situation of persons with MS living in long-term care facilities and makes certain recommendations concerning the reorganization and planning of the residential resources and services available to this clientele.

GAGNON, Daniel; MICHAUD, Annie. *Avis sur l'hébergement en milieux de vie substituts pour les aînés en perte d'autonomie*. Québec, QC: Conseil des aînés, 2000, 85 p. (M6613)

This document looks at the current situation in public and private residential centres for seniors who are losing their autonomy, and highlights frequent problems and the current and future needs of those who benefit from these services. It also raises the concerns of the Conseil des aînés and sets out recommendations to improve the situation.

Regroupement de parents de personne ayant une déficience intellectuelle de Montréal. *Vers un accès accru à des services résidentiels de qualité*, Montréal, QC: Regroupement de parents de personne ayant une déficience intellectuelle de Montréal, 1997, 29 p. (A6819)

This document outlines the needs of persons with intellectual impairments in terms of residential services, and recommends a series of measures aimed at improving them.

**By Myriam Thibault**

*To borrow any of the above, or for more information, feel free to contact the Documentation Centre team at (514) 873-3574 or 1-888-264-2362 toll-free, or by e-mail at [documentation@ophq.gouv.qc.ca](mailto:documentation@ophq.gouv.qc.ca)*

## INNOVATION

### **To improve communication**

On January 21, a research report<sup>1</sup> on communication was launched. This research project was undertaken following the adoption, by the City of Montréal in 2002, of the principle of universal accessibility. This principle is defined as the elimination of all barriers (physical, social and communication-related) that can prevent people from carrying out their activities. Accordingly, access to information for persons with intellectual impairments or speech disorders corresponds to the definition of this principle.

The Comité régional des associations pour la déficience intellectuelle (CRADI), a regional committee representing intellectual impairment associations, in conjunction with researchers from the Groupe DÉFI apprentissage of the Université de Montréal, was mandated by the City of Montréal to coordinate an initiative intended to identify the communication needs of people with such impairments. The ensuing report is the result of interviews conducted with the various partners and an analysis of the literature in the field. The purpose was to determine the specific communication needs of persons with intellectual impairments or speech disorders in a context where they are integrated into the community, and to report on the work done concerning the methods used to reduce their exclusion and dependence.

The researchers begin by defining various concepts such as accessibility, person with reduced mobility, person with a disability, barrier and handicap situation. They then review the legislation in force in Europe, the United States and Canada, and deal with specific communication needs by impairment in accordance with the municipal mission. Lastly, an analysis of the literature in the field looks at the situation in terms of physical accessibility, the accessibility of information and the accessibility of Web-site content.

In closing, the researchers observe that the initiatives and resources developed elsewhere, although interesting, do not adequately meet the needs of persons with intellectual impairments or speech disorders. However, they do provide avenues worth exploring and improving upon. Work will be carried out to clarify the situation and identify the most effective ways of overcoming obstacles as part of the second phase of the project. Truly a swiftly developing sector! To obtain a copy of this report, please contact Mélanie Paré of the Groupe Défi Apprentissage at (514) 343-6111, extension 2158.

**By Micheline Thibault**

<sup>1</sup> Rocque S., Langevin, J. et Paré M., *Information et communication municipale dans une optique d'accessibilité universelle – Phase I – Les besoins spécifiques de communication et les mesures existantes pour favoriser l'accessibilité aux personnes qui ont des incapacités intellectuelles ou des troubles du langage et de la parole*, Groupe DÉFI Apprentissage (Université de Montréal) and the Comité régional des associations pour la déficience intellectuelle, 2004, 37 p.

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