# **Rehabilitation centres**

The mission of rehabilitation centres is to offer adjustment, rehabilitation and social integration services to people with behavioural, psychosocial or family problems resulting from physical and intellectual disabilities because of alcoholism or another drug addiction require such services along with support and guidance services for their family circle.

# Type of complaints

#### Complaints reviewed by the Québec Ombudsman

Rehabilitation centres									
Under investigation at April 1, 2007	Received		Under investigation						
		Referred	Interrupted	Unsub- stantiated	Substantiated	at March 31, 2007			
61	42	-	4	18	17	43			

\* Excluding complaints whose processing was interrupted or which were referred.

#### Results of the review of complaints

Category	Inquirers*	Complaints*	Unsubstantiated	Substantiated	Number of corrective measures
Clinical aspects	12	16	6	10	19
Financial aspects	2	2	1	1	1
Environment and living environment	4	5	3	2	3
Programs and services	12	12	8	4	8

\* Excluding complaints whose processing was interrupted or which were referred.

# Overview of the situation

The aging of the population, increasingly precise and early diagnoses, technological advances and improved medical expertise all result in a growing number of requests for rehabilitation and adjustment services.

Despite the efforts aiming to improve availability, delays are still extremely long, particularly for children, whose development may be hindered, as well as for the elderly, who are not assigned any type of priority on waiting lists.

Since 2003-2004, the Ministère de la Santé et des Services sociaux has invested \$108 million in services for individuals with disabilities or pervasive development disorders, and has undertaken to disclose an access plan for rehabilitation services, the implementation of which to be funded from recent investments, in 2008.

## **Residential services**

Until the early 1980's, persons with intellectual disabilities were institutionalized. With a change in approach, growing support for deinstitutionalization and an acknowledgement of the rights of the disabled to a normal life, most of these persons now live with their families or in non-institutional residences integrated to the community.

These residences must offer a natural lifestyle these persons would have enjoyed, based on age and special needs. Coined "family-type" and "intermediary" residences, their daily administration is ensured by residence managers under contract with a rehabilitation centre for persons with intellectual disabilities or a pervasive development disorder. There are also continuing care residences mandated to intervene in a temporary but intensive manner with the aim of stabilizing users so that they can be directed to less comprehensive facilities.

Employees of continuing care residences, unlike those of non-institutionalized residences, report directly to rehabilitation centres. Québec currently counts over 1,000 persons with intellectual disabilities or a pervasive development disorder on the various waiting lists for residential services. This is extremely worrisome, particularly for aging parents who wonder as to the fate of their disabled child once they are no longer able to take care of them.

# Ombudsman follow-up and actions

#### Access to services : a major problem area

Access to physical rehabilitation services is still a serious problem in the vast majority of Québec regions, with delays of up to several years.

There are currently 3,500 children waiting to receive physical rehabilitation services, 2,000 of which for language-related disabilities. As for adults, there are nearly 6,000 of them on various waiting lists for services, close to half of whom are elderly. The average period before accessing services is seven months and can be as long as three years. A number of possible solutions are currently being evaluated. These include the willingness of professional agencies to allow non-professionals to dispense certain services, the introduction of a college program for language re-education certification, a widening of the scope of practice of various professionals favoring multidisciplinary teamwork, and the development of labour programs.

The Québec Ombudsman this year focused on persons who had been on waiting lists for over two years and where the institution was not able to provide a date by which they could benefit from the services they so desperately needed. In these particular cases, we asked the institutions involved to at least notify citizens of the estimated time period before they could receive services.

## Speech therapy services

The delay for speech therapy services is particularly of concern. Over the last year, the Québec Ombudsman was contacted by the parents of children who had been on waiting lists to receive speech therapy services for over 36 months. During early child-hood development, such a delay can cause major and permanent damage to children.

Depending on the region involved, delays are due either to a lack of funding or shortage of labour. Furthermore several speech-language pathologists opt to practice in the private sector, where the working conditions are often deemed more advantageous. Some parents, worried about their child's development and tired of waiting, choose to consult a professional from the private sector. The high costs of these services effectively prohibit access for persons who are less financially well off or have no personal insurance coverage.

## The principle of continuity of services

Section 5 of the Act respecting health services and social services decrees that every person is entitled to receive, with continuity, health services and social services. The following two complaints, brought to the Québec Ombudsman's attention over the last year, clearly exemplify instances where the provisions of this section were not abided by.

#### Back to square one

A child who was receiving services at a rehabilitation centre was placed on a waiting list to receive similar services following his family's move to another region. The child's parents were aghast that they had not been warned that their child would once again have to be put on a waiting list. The Québec Ombudsman reviewed the complaint, subsequent to which the family once again began receiving the necessary services.

# 10 years of services later, a citizen loses everything after moving

An adult with disabilities who had for ten years enjoyed an exceptional measure under which he was refunded the cost of his medical supplies, as originally provided for by the Office des personnes handicappées du Québec's former visual aids program, lost his assistance when he moved to a new territory where the agency did not allow exceptional measures.

The Québec Ombudsman is concerned about the lack of information provided citizens who are moving, primarily with regard to loss of services, waiting times and the ensuing measures to be taken ahead of time. We are also concerned by the ad hoc management of these situations and the lack of consideration for the plight of these persons. The non-continuity of services directly affects the quality of life of persons with disabilities and that of their families.

## Access to residential facilities

Most of the complaints submitted to the Québec Ombudsman over the past year by citizens with intellectual disabilities or a pervasive development disorder involved residential services. The matters brought to our attention included the availability of residential facilities, particularly in the case of adults, the safety and quality of the services offered by these facilities as well as their geographic remoteness and the attitude of staff.

The availability of accommodations is still sparse in the vast majority of regions. Waiting periods can be as long as two years, with the facility offered sometimes located far from the family residence. The most often cited explanations for delays are a difficulty in recruiting new resources and the lack of funds. In this regard, the Politique de soutien aux personnes présentant une déficience intellectuelle, à leurs familles et aux autres proches (2001)<sup>36</sup> requires that rehabilitation centres offer substitute living environments that accommodate no more than four people.

Seeing as numerous non-institutional residences had obtained a licence to accommodate up to nine users, many of them were left with empty spaces. This notably occurred because of the difficulties inherent in pairing users with different needs. Whereas recruiting new residential facilities to accommodate four or less persons is difficult, given that it is less attractive financially.

## Safety and service quality in non-institutional residences

The professional practice of family-type and intermediary residences is structured by department orientations based on quality standards that are consistent from one region to the next. Rehabilitation centres for persons with intellectual disabilities or a pervasive development disorder are responsible for adherence to these standards, so as to ensure the safety and well-being of this particularly vulnerable group of users.

<sup>36</sup> Ministère de la Santé et des Services sociaux, De l'intégration sociale à la participation sociale : Politique de soutien aux personnes présentant une déficience intellectuelle, à leurs familles et aux autres proches, Québec, 2001, p.59.

Below is an example of a residence visited on a number of occasions where, despite the existence of alarming factors, no one considered that an investigation might be appropriate.

#### It took a mother's intervention to shake things up

A mother arrived at the residence where her severely disabled daughter was being kept and immediately noticed that she had lost weight and exuded a foul stench. She deplored the fact that during her entire visit that day, namely from 11:30 a.m. to 3:30 p.m., no food or beverages had been offered to the residents, no diapers had been changed ,that a foul stench pervaded the entire residence and the room temperature was extremely low. She also deplored the fact that the residence manager never assisted any of the users. The following morning, the mother notified an employee at the rehabilitation centre for intellectual disabilities of what she had seen, expressing her fears for the safety and health of the persons living in this residence. The residence was finally shut down three months after the mother had raised the alarm.

The complaint was submitted to the Québec Ombudsman after the centre's closing. It focused on the fact that despite numerous visits by employees of the rehabilitation centre for intellectual disabilities, no one had ever asked the institution's authorities to conduct an investigation into this residence. The complaint also criticized the fact that three months went by between the mother's report and the shutting down of the residence.

The Québec Ombudsman's investigation unearthed an obvious lack of communication between the various actors, poorly defined responsibilities, a lack of knowledge of the various parties' responsibilities vis-à-vis suspected abuse or negligence, and the lack of an actor responsible for monitoring each user.

Subsequent to the Québec Ombudsman's intervention, management at the centre clearly reminded all staff working with users of their obligation to report any suspected instances of user abuse or negligence to the proper authorities.

The Québec Ombudsman also ensured that a person be named in charge of the action plan and follow-up for each user living in a residential facility. These persons are mandated to ensure the well-being of the persons under their responsibility.

#### Socioprofessional services

The aim of these services is to enable persons with a pervasive development disorder or intellectual disabilities to develop various skills so as to enter or remain in the labour market, or if this is not an option or not desired, to develop skills and strategies promoting their social integration or participation in important and enhancive activities.

## Believing in the potential of persons with intellectual disabilities

The mother of a young adult with mild intellectual disabilities deplored the fact that the rehabilitation centre underestimated her son's abilities and subsequently limited his work-related activities to two and a half days a week. She would like to see him doing activities that fully promote the development of his skills five days a week.

The Québec Ombudsman concurred with the mother recommending that the institution amend the young adult's intervention plan so as to incorporate an action plan that specifically included elements enabling him to acquire new skills. It also recommended that steps be resumed to find important and fulfilling activities so as to keep the young adult busy five days a week.

# Difficulty obtaining specialized speech therapy and occupational therapy services

A mother whose son was diagnosed with a "pervasive development disorder" when he was 17 months old filed a complaint with the Québec Ombudsman. She felt that her son's urgent and pressing needs were not being met by the regional rehabilitation centre for physical disabilities in a timely fashion.

In reality, six months went by from the time the rehabilitation centre received a treatment request from a hospital centre to the moment it held its first exchange with the mother regarding her son's needs. The mother turned to professional services in the private sector during this interim. The Québec Ombudsman, considering such a delay unreasonable, recommended that the institution remind the personnel concerned of the stipulated onemonth time period between the acceptance of a treatment request and the first contact with a user's family.

The Québec Ombudsman is of the opinion that the rehabilitation centre for intellectual disabilities can only fulfil its mandate through a close cooperation with its privileged partner, in this case the rehabilitation centre for physical disabilities.

# 2007-2008 recommendations

Given that it will take a few years for the impact of the measures introduced to compensate for the lack of speech therapists to be felt;

Given that early intervention is acknowledged as a means of maximizing the rehabilitation potential of persons with disabilities;

Given that long waiting periods are exhausting for parents, seriously damage and compromise the overall development of children, particularly with regard to school integration, and create social isolation;

Given that there are currently over 2,000 children on Québec waiting lists for speech therapy services;

THE QUÉBEC OMBUDSMAN RECOMMENDS :

That the Ministère de la Santé et des Services sociaux take the necessary measures to implement special access mechanisms for making speech therapy services available within a reasonable timeframe.

Comments from the department

The following statement from the department was issued by its Deputy Minister :

"Measures enabling us to follow up on this recommendation were incorporated to the rehabilitation access plan."