Adequate Living Conditions for Adults with Multiple Sclerosis Residing in Long-Term Care Facilities: A Challenge To Be Met…Without Delay

White Paper presented by the Multiple Sclerosis Society of Canada (Quebec Division)

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The Multiple Sclerosis Society of Canada (Quebec Division) believes that people with multiple sclerosis should be helped to remain in their own homes as long as possible. Nevertheless, those who, due to their illness, must resign themselves to leaving their homes, are faced with a hard reality.

Long-term care facilities, remember, were designed for the elderly. People with MS who move into such facilities are often only 20, 30 or 40 years old. Various personal accounts have told us of the many problems with cohabitation of the two groups (adults and the elderly).

We consider it essential to rethink the organization and planning of resources and services for the multiple clienteles housed in Quebec’s health and social services institutions, with a view to offering adults alternatives to traditional institutionalization.

Our paper deals with adults with multiple sclerosis who live in long-term care facilities. These people are generally able to assume a fair share of social responsibility and participate in community life, especially since they do not have major psychological problems. The greatest difficulty encountered by many of these adults is finding themselves in an environment where the great majority of those around them are elderly, and sometimes very old.

Another factor that should be considered is the cost of housing. The loss of employment, sometimes inevitable, and the resulting financial hardship can turn life upside down for a person or couple affected by MS. For a spouse who does not receive disability benefits and who must “institutionalize” his or her partner, the financial burden is generally devastating. This is particularly true when the couple has young children. In this respect, their situation is radically different from that of senior citizens whose offspring are usually financially independent.

Everyone agrees that it is essential to feel at home to maintain sound mental health and a normal quality of life. An overall understanding of the needs of adults with MS has shown us that there are three types of needs that are not met in many long-term care facilities.

Physical Needs

Scheduling inflexibility and overworked staff often lead to problems with personal hygiene, bathing frequency and restrictions on time spent out of bed. Of course, these factors have a negative impact on the quality of life for all the residents, both adults and seniors.

However, another factor has a direct, more exclusive impact on the quality of life and health for people with MS: the ambient temperature in the institutions is too high.

Psychological and Emotional Needs

Cramped quarters in the rooms and/or the high number of roommates means a lack of privacy and there is no place to get together with family and friends. Once again, this is a problem for both seniors and adults.

Cohabitation of clienteles is often difficult, especially when an adult is isolated among very elderly people. This is all the more true when the seniors are confused or suffer from dementia.
The break with the natural environment, the fear of losing their identity, and the lack of accommodation for spousal relationships are, unfortunately, all elements that can lead to deterioration in these young adults who, despite their disease, still have interests and abilities that cannot be served due to the lack of resources.

Furthermore, the lack of acknowledgement of the residents’ potential can be detrimental to self-esteem. These people still have a lot to offer if they are given the opportunity. For example, they can pay friendly visits to elderly residents who have no visitors, or they can organize social activities for the adults.

**Social, Recreational and Cultural Needs**

In some long-term care facilities, the rigid structure of the services prevents planned outings with volunteers. This accentuates the feeling of isolation.

Programs and activities are designed for the majority, i.e., seniors, so the adults suffer from a lack of social contact with their peers and the inaccessibility of services and activities suited to their interests and to their need for a minimum personal control over their lives.

In some facilities, there is a lack of support for families and volunteers who would get more involved. Children should be encouraged to visit their parents in the residence and the existence and needs of the couple should be acknowledged. Institutions have everything to gain by encouraging such relationships.

**Alternatives to Institutionalization**

The Multiple Sclerosis Society of Canada strongly recommends that a network of long-term care facilities be developed to meet the needs of adults with MS who can no longer stay home. This would make it possible for this clientele not only to share specialized human and material resources, but also to organize activities, programs and services suited to their needs. This network could include existing long-term care facilities that have been restructured for younger users, as well as small residential projects such as the substitute living environment.

There are already a few promising examples of conversion of health and social services facilities in some areas. Various methods have been used: reserving one floor or wing of a long-term care facility exclusively for adults with MS or another chronic disease; partnering with non-institutional networks to develop substitute lifestyle environments that are staffed 24 hours a day; providing training on MS within the facilities themselves. Still few in number, these initiatives nevertheless warrant attention and should provide inspiration for the reorganization of services for adults with multiple sclerosis.

This paper describes some examples of successful initiatives: the Ulysse Gauthier residence in Granby, the service islands at the Centre de réadaptation Lucie-Bruneau in Montreal, and the Lajemmerais residence attached to the CHSLD du Littoral in Varennes.

Institutionalization should always be a last resort or an enlightened choice by the adult concerned. For adults (as opposed to seniors) who absolutely must leave their home, the Society urges that more specialized residential facilities be developed: facilities like the Ulysse Gauthier residence and the Centre Lucie-Bruneau service islands. The projects inspired by these experiments should not require additional funding, but would certainly involve reorganization of the existing structures and resources.
1. The Context

Our paper is based on a perception that has been borne out on a daily basis for several years. A good number of groups and citizens are already involved, jointly or individually, in this endeavour to provide better living conditions for adults with severe physical disabilities who can no longer remain in their home.

Not all people with multiple sclerosis (MS) have to resign themselves to leaving their home one day. On the contrary, some, according to the course of their disease, have much lighter functional limitations and many of them find their limitations alleviated through the support of friends and family members, natural caregivers, community health care clinics, or service organizations. The Multiple Sclerosis Society of Canada would prefer that people remain in their natural environment: this will always be less of a burden than institutionalization. The latter option should only be considered when no other avenue is available.

As we will show later, the needs of people over 18 and under 60 who have MS and must move into long-term care facilities (CHSLDs) are different from those of the majority of these institutions residents, namely the elderly. (In this document, we refer to the first group as “adults” and the second group as “seniors” or “the elderly”.)

Long-term care facilities, remember, were designed to house senior citizens. People with MS are usually only 20, 30 or 40 years old when they arrive in such facilities. Various stories of personal experiences have shown us that many problems arise from the cohabitation of the two groups (adults and seniors).

Available statistics for the Province of Quebec do not identify the number of adults living in long-term care facilities according to the type of illness. Nevertheless, the absence of “official figures” does not obliterate the real problems these adults are faced with. Even though they are a minority compared to seniors, there is a good number of them and it is essential that their physical, psychological and emotional needs be appropriately met.

Added to this is the fact that the Quebec population is ageing, which will mean a significant increase, in a few years’ time, of the need for residential and health care facilities.

Based on the above observations, it is our opinion that the organization and planning of resources and services for the multiple clienteles living in Quebec health and social services institutions need to be rethought now so that adults can be offered alternatives to traditional institutionalization.
Some long-term care facilities (and other health and social services institutions) have already taken steps to provide an environment and services more suited to adults’ needs and values. However, this is by far not the case for all such facilities. The purpose of this white paper, therefore, is to make the MS Society’s position known. The MS Society endorses the Quebec law dealing with the existence of residential and long-term care centres (CHSLDs), an act based on the principle of “citizens first”:

The mission of a residential and long-term care centre is to offer, on a temporary or permanent basis, alternative environment, lodging, assistance, support and supervision services as well as rehabilitation, psychosocial and nursing care and pharmaceutical and medical services to adults who, by reason of loss of functional or psychosocial autonomy can no longer live in their natural environment, despite the support of their families and friends.

(Bill 120, section 83 on the mission of the residential and long-term care centre, 1992)

Our belief in this legislation requires that we all strive to put it into practice.

Some current aspects of institutional life indicate that to be true to this mission, long-term care facilities should be able to obtain additional resources (human and financial) to respond better to the needs of both adults and seniors. This is not, however, the objective of this white paper, and we will focus on the reality of adults under the age of 60 with multiple sclerosis who must leave their home because of their physical disabilities. We will endeavour to bring out the issues related to their institutionalization and suggest ways that might help make it possible to meet all of their needs more adequately.
2. The Multiple Sclerosis Society of Canada

Stories

For ten years, stories of personal experiences have been collected by the Multiple Sclerosis Society of Canada, Quebec Division, via the Society’s chapters. These stories speak for themselves: they relate experiences that are sometimes satisfactory, very often unsatisfactory, of adults in long-term care facilities. To protect anonymity and confidentiality, the names have been changed and the locations of residences, volunteer work or jobs of the people concerned have not been divulged. When available, the year of the story is included.

When people with multiple sclerosis receive excellent institutional care, it is because more is required of their caregivers as their needs are different from those of the elderly.

The Multiple Sclerosis Society of Canada was founded in Montreal in 1948. It had a dual mission: to lead the search for a cure for multiple sclerosis (MS) and to help people with the disease enhance their quality of life.

Today, the MS Society has 28,000 members, 6,000 of whom are in Quebec. The MS Society is represented in Quebec by the Quebec Division, which operates independently.

1. Support for MS Research

The MS Society supports research and clinical trials at the MS Clinics in Canada. In Quebec, five specialized clinics provide diagnostic services and treatment for MS and do research on the disorder:

- The MS Clinic at Notre-Dame Hospital in Montreal
- The MS Clinic at the Montreal Neurological Institute
- The MS Clinic at the Centre universitaire et de la santé de l’Estrie
- The MS Clinic at the Institut de réadaptation en déficience physique in Quebec City
- The MS Clinic at the Neuro Rive-Sud in Montérégie

2. Support Services

Directly or through its chapters, the MS Society Quebec Division offers a number of services:

- Information on research and the various aspects of the disease (documentation, information sessions, lectures, etc.);
- Awareness programs for volunteers and health professionals to help them serve people with MS as effectively as possible;
- Psychological support;
- Social and recreational activities;
- Advocacy and social action.
2. The Multiple Sclerosis Society of Canada (continued)

Stories

People with MS need to communicate, build relationships, live and experience life like anyone else. All too often, they find themselves alone, isolated, with nothing to do and nothing to say.

The physical environment is sometimes very comfortable, especially when the buildings are new and designed with the residents’ well-being in mind. However, sometimes the psychological environment is far from healthy for the emotional well-being of a relatively young person with MS.

3. The MS Society’s Twenty-six Chapters in Quebec

Abitibi          Manicouagan
Montreal West Island    Mauricie
Lower Laurentians    Montérégie
Bonaventure         Mont-Laurier
North Shore         Montreal
Drummondville       Outaouais
Estrie (Sherbrooke)  Quebec City Region
Estrie (Windsor)     des Moulins Region
Haute-Yamaska       Rouyn-Noranda
Lac-Saint-Jean       Saguenay
Lakeshore            Saint-Hyacinthe
Laurentides          Sorel-Tracy
Laval                Thérèse-de-Blainville

Organizations like the chapters of the Multiple Sclerosis Society of Canada can be a determining factor in responding to the needs of young adults in institutions. Through the training they offer and the relevant information they distribute, these groups are able to provide indispensable support to the residents of long-term care facilities and help the caregivers understand the impact of the disease on the individuals and their entourage. This type of collaboration benefits both the institutions and the “patients” because it generally improves the circulation of information among the users, institutional staff and families and friends. When the support groups draw closer to the staff members looking after young adults with MS, the quality of life inside and outside the institution is much improved.
3. Multiple Sclerosis: A Neurological Disorder

Multiple sclerosis is a chronic disease of the central nervous system (brain and spinal cord). The myelin sheathing is destroyed, which disrupts the transmission of nerve impulses. MS has many symptoms and sometimes various types of medication are required to relieve them.

Specialists have defined four types of MS:

- **relapsing remitting**: clearly defined disease relapses (flare-ups) with full recovery, with or without residual deficit; lack of disease progression between relapses; the most frequent form;
- **primary-progressive**: disease progression from onset, with occasional plateaux and possible temporary minor improvements;
- **secondary-progressive**: progression with or without relapses, minor remissions and plateaux; this form follows the relapsing-remitting type and generally occurs after 10 to 15 years of disease progression;
- **progressive-relapsing**: progressive disease from onset, with acute relapses, with or without full recovery; periods between relapses characterized by continuing progression.

Two other forms are associated with these four:

- **benign MS**: few relapses with long periods of remission and minimal disability after 15 years.
- **malignant MS (very rare)**: rapid progression of the primary-progressive form within five years of diagnosis, leading to significant disability.

Multiple sclerosis progresses differently from person to person and from one form to another. Unfortunately, over the years, the disease often leads to major loss of autonomy, which obliges people to leave their homes. Once a person needs more than 3 hours of care per day and the people around him or her cannot provide it, the person is obliged to move into a private or public long-term care facility.

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**Stories**

*Jacques is 22. He needs to see people his own age. He likes to go shopping, listen to sentimental music, watch movies that interest him.*

*Louise is 45 and has to go to bed at 7 p.m. every night because that is the time assigned to the entire floor.*

*Marjo is 40 and is pining away in an environment for seniors who can no longer care for themselves. She has decided to make life impossible for herself by shutting out anything positive in her existence which she says is over. MS is wasting her physically, the unsuitable environment for a young, intelligent woman is destroying her psychologically. She simply rejects her life as it is now. So she remains in bed in a totally dark room. The only stimulating activity she allows herself is watching television. She is cynical and very unhappy.*

(1998)
3. Multiple Sclerosis: A Neurological Disorder (continued)

Stories

A former ballerina, Madeleine enjoys talking and active listening in her room, where she is confined to her bed all day.

Michel is new to MS and lives in a long-term care facility. He has young children and believes that his spouse, who comes to see him very often, would benefit from some support and active listening.

Everyone needs to be listened to and to make friends; we all need to have fun.

Régine, age 30, is confined to bed. She gets up very rarely now since a severe relapse last spring. Because she is considered to be an invalid, she will soon have to move to another room because the room she is in is for “semi-invalid” patients.

Most deplorable is that some of our members only get out of bed two to six times a week for about three hours at a time. The rest of the time, they are in bed staring at the walls and ceiling or watching television, if they have one.

Facts About MS

- Multiple sclerosis is usually diagnosed in people between the ages of 20 and 40. It strikes women more often than men. MS is the most wide-spread nervous disorder among young adults. Quebec has one of the highest prevalence rates of MS in the world.

- MS produces a wide range of symptoms that vary from person to person and from time to time for the same person. The symptoms can include extreme fatigue, slurred speech, vision problems such as diplopia (double vision), nystagmus, and, in some cases, blindness, difficulty walking, stiff joints, bladder and bowel dysfunction, tremor, loss of balance, even paralysis.

- Other symptoms are harder to detect because they are not visible to the naked eye. These include various sensory problems, such as hypersensitive skin, hypersensitivity to heat, numbness, itching, etc.

- MS is not a mental disorder, nor is it contagious. Its cause, however, is still unknown and there is no cure.

- Since it occurs early in adulthood, the psychological impacts of the disease can be considerable. Loss of employment, sometimes inevitable, and the resulting financial hardship can overwhelm a spousal relationship, reduce the quality of life and put constraints on a proper response to the physical, social, psychological and emotional needs of the person with MS. For spouses who do not receive disability benefits and who must “institutionalize” their partner, the financial burden is usually devastating. This is particularly true when the couple has young children.

- There are currently four treatments for the relapsing-remitting form of MS. They can reduce the frequency, intensity and duration of relapses. In so doing, they slow down the progression of the disease. They also reduce the number of new brain lesions detected by magnetic resonance imaging. There is also one treatment for the progressive-secondary form. At the moment, however, there are no specific treatments for the primary-progressive or progressive-remitting forms of multiple sclerosis.
4. The Problem: Adults Have Specific Needs

*S t o r i e s*

Danielle, age 40, is a quadriplegic. She has lived in an institution for 10 years. Her privacy is inconvenienced by wandering seniors; a number of residents go into her room and touch her, and she is unable to call for help. (1998)

Maggie has lived in the residence for two years because she is almost totally paralysed. She can sit in her wheelchair due to an antispasmodic abdominal implant that she received several months ago. She considers herself well off despite her condition and has resigned herself to it over time. However, she finds the heat uncomfortable. (1998)

Work methods lack humanity. Whatever happened to respect and consideration for sick people? It makes you wonder.

This paper is concerned with long-term care facility adult residents with MS. Despite their illness, these people are generally able to assume a fair share of social responsibility and participate in community life, especially since they do not have major psychological problems. The main difficulty encountered by most of these adults is finding themselves in a living environment where the great majority of the people around them are elderly, sometimes very old.

This complex problem requires juggling the various difficulties involved in serving a mixed clientele of seniors and adults with MS or other chronic illnesses – quadriplegia, spina bifida, or muscular dystrophy, for example.

The ageing population will increase the demand for residential services, and the issue of providing services for adults in long-term facilities will become even more critical.

Everyone agrees that it is essential to feel at home in order to maintain sound mental health and a normal quality of life. An overall understanding of the needs of adults with MS has shown us that there are three types of unsatisfied needs in many long-term care facilities.

1. Physical Needs

Scheduling inflexibility and overworked staff often lead to problems with personal hygiene, bathing frequency and restrictions on time spent out of bed. These factors naturally have a negative impact on the quality of life for all the residents, both adults and seniors.

On the other hand, another factor has a direct, more exclusive impact on the quality of life and health for people with MS: the high ambient temperature in institutions can be detrimental to people with MS, whereas the elderly often feel cold. It is usually recommended that people with MS pay careful attention to the temperature of their environment, which is unfortunately impossible for those who live in long-term care facilities, unless special measures have been taken to deal with this problem.

2. Psychological and Emotional Needs

Cramped quarters in the rooms and/or the high number of roommates end up in a lack of privacy while there is no place to meet with family and friends. Once again, this is a problem for both seniors and adults.
4. The Problem: Adults Have Specific Needs (continued)

**Stories**

Joanne, a 40-year-old paraplegic, has lived in an institution for four years. She is very isolated, has only a few visitors, does not participate in activities. Joanne is disturbed by the cries and constant noises made on the floor by other patients who suffer from psychological disorders. She would like to have a floor reserved for patients with MS. This would enable her to meet and talk with people in the same situation as hers’. (1998)

As previously mentioned, cohabitation of clienteles is often difficult, especially when an adult is isolated among very elderly people. This is all the more true when the seniors are confused or suffer from dementia.

Seniors, as everyone knows, rarely welcome the move into an institution. For someone who is 20, 30 or 40 years old, this situation is even more alarming, especially when the person knows he or she will be isolated among elderly people.

There is also a risk of identity loss for an adult with severe physical limitations but whose lucidity and intellectual faculties are intact. The disparity between the two aspects of a person’s condition may partly explain the reputation of “demanding customers” that is sometimes attributed to young adults with MS.

The break with the natural environment, the fear of losing their identity and the lack of accommodation for spousal relationships are, unfortunately, all elements that can lead to deterioration in young adults who, despite their disease, still have interests and abilities that cannot be served due to the lack of resources.

Furthermore, the poor acknowledgement of the residents’ potential can be detrimental to self-esteem. These people still have a lot to offer if they are given the opportunity. For example, they can pay friendly visits to elderly residents who do not have visitors, or they can organize social activities for their peers.

3. Social, Recreational and Cultural Needs

In some long-term care facilities, the rigid service structure prevents planned outings with volunteers. This only accentuates the adults’ feeling of isolation.

Furthermore, programs and activities are designed for the majority, i.e., seniors, so many adults suffer from a lack of social contact with their peers and the inaccessibility of services and activities suited to their interests and values.

In some facilities, there is also little if no support for family members and volunteers who only ask to be involved. In fact, visits by children to their parents should be facilitated in long-term care facilities, and the existing couples’ particular needs should be acknowledged. Institutions have everything to gain by encouraging such relationships.
5. **Alternatives to Institutionalization**

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**Stories**

*Most of the MS Society members who live in institutions are young and generally feel depressed because their environment is designed for people who are psychologically unable to care for themselves and suffer from Alzheimer’s, etc. With MS, isolation sets in because the person cannot get around alone and because young adults generally withdraw from society. Heat is also an inconvenience that makes life difficult. (1998)*

*Letter to the Minister: [...] describing the context of my admission to and residence in a long-term care facility, a situation that I consider traumatizing at the age of 46, and that I still am unable to accept [...] I ask that the solution suggested to me nearly a year ago to move into accessible housing finally be made possible so that I can live out the coming years in a socially more suitable environment where I can enjoy a more independent, better quality life based on the needs and expectations of a person my age, for whom living amid people who are much older is not the solution. (1998)*

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The Multiple Sclerosis Society of Canada strongly recommends that a network of long-term care facilities be developed specifically for adults with MS who can no longer remain at home. This would make it possible not only to pool specialized human and material resources for these users, but also to organize activities, programs and services suited to their needs. This network could include existing long-term care facilities that have been restructured for a younger clientele as well as smaller residential projects like the substitute living environment. Although in the short term the development of such a network would require funding for restructuring, there is no doubt that in the long term the network would not cost any more, and would even make better use of resources.

In some areas, there are already a few promising examples of conversion of health and social services facilities. The institutions that adopted such innovative approaches have acknowledged the urgent need to restructure the services available for adults.

As we will see, this has been done in various ways: by reserving one floor or wing of a long-term care facility exclusively for adults with MS or another chronic disease; by partnering with non-institutional networks to develop substitute living environments staffed 24 hours a day; by providing training on MS within the facilities themselves, etc. Still few in number, these initiatives nevertheless warrant attention and should provide inspiration for the reorganization of services for chronically ill adults. Some successful projects already in operation are described below.

In Granby, the Ulysse Gauthier residence is the result of close collaboration between the CHSLD Horace-Boivin, the Granby Hospital, the Haute-Yamaska CLSC (community health care clinic) and the Haute-Yamaska chapter of the Multiple Sclerosis Society of Canada. Thanks to their combined efforts, this residence can now house eight adults (five of whom have MS), and focus on the individual and the response to his or her physical (1), psychological and social (2) needs. The Horace-Boivin foundation financed the construction of the residence. This project is an unqualified success, as evidenced by the high satisfaction level of the residents and their families. The partners in the Ulysse Gauthier residence successfully developed an alternative to hospitalization and institutionalization to meet current and future needs.
5. Alternatives to Institutionalization (continued)

Stories

An innovative project!

The Entre-Deux residence, in conjunction with the CLSC des Forges, houses 12 people under the same roof, each in their own living quarters. These people receive home-care services 24 hours a day, 7 days a week.

As a group, they can pool their hours of home care and maintain continuous quality service. All this in addition to bringing handicapped people into society. The project meets the home-care standards of the regional health-care authorities.

Among the residents at Entre-Deux are handicapped adults, people with cerebral palsy, adults with MS. People with fairly severe MS say they are happy with the care they receive because they say they have learned to accept their illness. The worst nuisance is the heat. (1998)

At the same time, the CHSLD Horace-Boivin alleviated the strain on institutional resources and by respecting the different missions, encouraged strategic partnerships between institutional, private and community facilities. It also created a stimulating environment for the residents, which is as close as possible to a normal living environment, and open to the community.

In Montreal in the 1970s, the Centre de réadaptation Lucie-Bruneau set up long-term care facilities called “service islands”. These are apartment groups in a building staffed around the clock by Centre de réadaptation personnel who provide the services residents need. These are independent, leased apartments where the residents live alone or with someone else. Meals are prepared and eaten with the group. Like the Ulysse Gauthier residence, the advantage of this type of facility is that the people who live there can continue to be independent but still have access to a qualified staff and community life.

Connected to the CHSLD du Littoral in Varennes, the Lajemmerais residence received a grant to reserve a wing for adults with MS between the ages of 50 and 60. People live at their own pace in a residential setting with the help of a regular staff. This is not the only avant-garde idea at Lajemmerais: another wing is reserved for some fifteen younger adults with MS. The employees responsible for the unit volunteer to take part in certain activities. Outings are organized using accessible transit. This facility and its staff also put a lot of effort into developing and providing an innovative environment and programs that meet the needs of young adults with MS.

These are only a few examples of successful initiatives. Their common denominator: a true concern to give adults with MS an environment suited to their needs. Unfortunately, these examples are still so few and the demand far exceeds the available space in these facilities, be they “restructured” long-term care facilities, or substitute living environments.

(1) Getting up, transfers, nutrition, even installation of a remote control system for such devices as the television, radio and telephone for a severely handicapped resident with MS who can use a straw to operate the system and live much more independently in his own living quarters.

(2) Space organization for receiving spouses and children, participation of the residents in decisions about menu selections and activities, etc.
6. Recommendations

Adults who are no longer self-sufficient continue to grow just like any other people. Whenever possible, the Multiple Sclerosis Society of Canada feels that these adults should remain in their natural environment, with help from community health-care clinics, service organizations, and such groups as the Multiple Sclerosis Society chapters. Institutionalization should become a sort of last resort, or an enlightened choice made by the adult concerned.

With regard to adults who absolutely must leave their home, the MS Society strongly recommends that more specialized housing be developed for this clientele, e.g. the Ulysse Gauthier residence and the Centre Lucie-Bruneau service islands.

We understand that limited budgets require self-help, maximum use of existing resources, and closer ties with outside resources. Nevertheless, we believe that people’s needs should always guide the planning and organization of services.

Furthermore, the issue of ambient temperature should be looked into. Unfortunately, people with MS suffer from the heat in most long-term care facilities. Proper climate control should suffice to prevent this problem.

Note also that some adjustments require very little effort and investment. For example, in one facility in Annonciation, because of the building exposure, people with MS were housed at the end of the wings where rooms were not as warm as others in the building. In addition, the environment was spruced up as much as possible: some would go so far as to say that the place looks truly home-like! This is a major contrast with the situation at another long-term care facility in the area, where a lady with MS was forbidden to decorate her own room!

All citizens are entitled to live in a safe, adequate, warm environment. This is why we recommend that the government decision-makers act on the following proposals.

1. Physical Restructuring

1.1. Set up more alternative or intermediate facilities specifically for adults with MS:

1.1.1. By developing communal “living unit” or “substitute living environment” residences. Grouping the beneficiaries in smaller projects makes it easier to plan services and marshal the human, material and environmental resources needed to create a stimulating, interesting living environment. (An example is the Ulysse Gauthier residence.)
6. **Recommendations (continued)**

1.1.2. By encouraging the adaptation of regular rental apartments, grouped in one building, and reorganizing the layout to accommodate people in need of daily assistance which can be obtained from the public health-care network and/or private resources and/or the community and their families. (Examples are the Centre Lucie-Bruneau service islands and the CLSC des Forges Entre-Deux project.)

1.2. Convert some existing long-term care facilities to accommodate chronically ill adults who, despite their young age, must leave their home.

1.3. Restructure some long-term care facilities that already have a mixed clientele by reserving wings or floors for groups of adults. (An example is the CHSLD Lajemmerais.)

2. **Reorganization of Human Resources and Services**

2.1. Provide training on MS for staff members in long-term care facilities. This training could involve representatives of the Multiple Sclerosis Society of Canada.

2.2. Develop activities and programs for adults with MS or other chronic illnesses that strike people in their prime. It is strongly recommended that these adults be involved in defining the goals to be achieved, because they are in the best position to determine their own needs in this regard. Recreation, outings, and some other activities should be organized. (This could be done in conjunction with the MS Society chapter nearest to the long-term care facility.)

2.3. Enable young adults who can no longer look after themselves to be located as close as possible to their natural environment so that their spouse, children and friends can visit them in their new accommodations without having to travel far. Design ways to allow spousal relationships, i.e., create a stimulating environment that meets spouses’ specific needs and promotes their involvement in activities that cater to their tastes, values and abilities.

As we stressed previously, additional human and financial resources are absolutely indispensable to improve the living standards currently found in most long-term care facilities, affecting both adults and the elderly.
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