

Equals in Every Respect:

Because Rights Are
Meant to Be Exercised

Government policy for increasing
the social participation of handicapped persons



Coordination, drafting and publication

Office des personnes handicapées du Québec

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Legal deposit – 2010
Bibliothèque et Archives nationales du Québec
Library and Archives Canada
ISBN for print version: 978-2-550-58015-7
ISBN for electronic version: 978-2-550-58016-5

Adopted by Cabinet on June 4, 2009

Printed in Canada

MESSAGE FROM THE PREMIER



The development of Québec society requires the contribution of every citizen. The social participation of handicapped persons, which undeniably enhances our society, is a priority issue in Québec.

The government's pledge to ensure the social participation of handicapped persons is not new. As early as 2003, at the opening of the 37th Legislature, I indicated that the government intended to amend the 1978 *Act to secure handicapped persons in the exercise of their rights*. On December 15, 2004, the National Assembly assented to Bill 56, which amended this Act.

The policy entitled *Equals in Every Respect: Because Rights Are Meant to Be Exercised* furthers the action undertaken by the Government of Québec and is a valuable instrument for increasing the participation of handicapped persons within Québec society and for greater respect of their rights. It is part of the suite of policies and strategies to foster the full participation of all Quebecers in our bid to build a more inclusive, unified and equitable society.

Insofar as this policy calls on all government sectors to play a role, it is the first of its kind adopted by Québec. This unprecedented initiative is a milestone that re-affirms the government's commitment to taking up the challenge of making Québec a place where handicapped persons are equals in every respect!

A handwritten signature in black ink, which appears to read "Jean Charest". The signature is fluid and cursive.

Jean Charest
Premier of Québec



MESSAGE FROM THE MINISTER FOR SOCIAL SERVICES



I am proud to present this government policy aimed at increasing the social participation of handicapped persons within a ten-year timeframe. Its adoption is proof that the Government of Québec is very serious about this goal. Like the *Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration*, the policy provides a solid footing for government action with regard to handicapped persons and their families.

Even now, all too often handicapped persons face a variety of barriers. These obstacles are such that action is required by every sphere and segment of Québec society. Admittedly, this makes the *Equals in Every Respect* policy ambitious precisely because the government's commitment must be seen as the momentum for widespread involvement by all public and private instances and by Quebecers as a whole.

Taking up the challenge of working to ensure greater social participation by handicapped persons is not only a collective responsibility—it is an individual one too. All Quebecers must pull up their sleeves and contribute to achievement of this goal because what handicapped persons have to give on the social, economic and cultural front is an invaluable asset that we cannot afford to waste.

Lise Thériault

Lise Thériault
Minister for Social Services



FOREWORD

In the past 30 years, major strides have been made in the social integration of handicapped persons in Québec. Part of the reason is the 1978 adoption of a legislative instrument that was ahead of its time, the *Act to secure handicapped persons in the exercise of their rights* (hereinafter referred to as the 1978 Act). Adopted unanimously in the National Assembly, this piece of legislation made the various public jurisdictions accountable for meeting the needs of handicapped persons. This was a first in Québec.

The 1984 *On Equal Terms* policy was an equally important milestone. The adoption of its guidelines by Cabinet in 1985 set the stage for the introduction of numerous policies and measures.

A few decades later it became necessary to adjust these tools to a new landscape. On December 15, 2004, the National Assembly of Québec adopted the *Act to amend the Act to secure handicapped persons in the exercise of their rights and other legislative provisions*, which substantially amended the 1978 Act. It provided new momentum for the social challenge of integrating handicapped persons and made all public and private players more accountable for achieving the goals of the Act.

The transitional provisions of this Act included the obligation to update the *On Equal Terms* policy and mandating of the Office des personnes

handicapées du Québec (hereinafter referred to as the Office) to carry out this task:

73. The Office des personnes handicapées du Québec must, no later than December 17, 2007, in cooperation with all the partners concerned by the school, workplace and social integration of handicapped persons, review the comprehensive policy entitled On Equal Terms.

The process

The Office began by conducting in-depth research that provided the latest information needed for it to assess the social participation of handicapped persons. In order to update the framework for the policy, serious thought had to be given to the goals, values and approaches to favour.

Throughout the autumn of 2006, public meetings were held across Québec. The aim was to inform the partners concerned about the process underway. They were encouraged to comment on the content, most of which dealt mainly with the values and principles associated with the objectives of a draft policy and with priority approaches.

The government was clear that this process was to be collegial. Numerous partners were enlisted through 17 pan-Québec issue tables composed of more than 80 organizations, and, on the regional level, through 16 committees formed to discuss issues and concerns specific to them. A monitoring committee created by the Board of Directors of the Office and an advisory committee of experts and representatives of the advocacy movement behind handicapped

persons kept abreast of the work and provided the Office with input throughout the process.

The resulting information was used to update the thematic progress reports produced as part of the consultation process and led to the definition of goals for reducing barriers to the social participation of handicapped persons. These results were also used to draft a consultation document sent to the partners in August 2007. A number of government departments and agencies and institutional groups were asked to give their opinion on this document, along with the advocacy community and the regional committees.

As part of this phase, the Office met with some 20 deputy ministers and government agency directors who commented on the document and made suggestions. It also processed the comments, opinions and suggestions received in writing from approximately 50 organizations. This feedback was analyzed and used to fine-tune and strengthen a draft policy.

On December 6, 2007, the Board of Directors of the Office adopted a draft policy entitled *Equals in Every Respect: Because Rights Are Meant to Be Exercised*. It was submitted to the minister responsible for enforcing the *Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration* (hereinafter referred to as the Act) the following December 17. The minister then set in motion a process leading to approval of the policy by Cabinet, which occurred on June 4, 2009.

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INTRODUCTION

A fundamental shift

The purpose of the policy before you, which is an indispensable complement to the Act, is to increase the social participation of handicapped persons in order to foster the genuine exercise of their rights and freedoms. This, of course, is contingent on making Québec society more inclusive, in other words, systematically taking into account the specific characteristics of handicapped persons and their families from the blueprint stage of any action on the physical or social front. Participation in full of handicapped persons in Québec society will hinge to a large extent on the efforts made in the next few years to prevent and eliminate anything that creates barriers leading to handicapping situations.

Québec is not yet as inclusive a society as it could be despite tangible gains since the 1978 adoption of the *Act to secure handicapped persons in the exercise of their rights* and release of the *On Equal Terms* policy in 1984. Thanks to ongoing lobbying by advocacy organizations, the Office and a number of public and private partners, an impressive suite of measures was introduced and great efforts were made to adapt the environment. All of these initiatives proved that investment in meeting the specific needs of handicapped persons and of their families was money well spent.

With the social, demographic, economic and political situation that prevails today, the need to strive towards a more inclusive society has come even more sharply into focus. It is much more costly

to adapt an existing house than to make inclusivity an integral feature “from the ground up.” The same is true of the broader physical and social environment.

Public transit is an excellent example of the above. Any improvements to it must meet the transportation needs of every citizen and must be made by pooling and maximizing existing resources.

Given the government’s limited resources and the greying of our population, which will necessarily mean more handicapped persons, it is imperative that their needs be foreseen systematically. Like environmental protection, this issue must be moved up on the scale of social priorities if we are to avoid more serious and pressing problems. This is why we must help all of Québec society make this fundamental shift and come together to introduce innovative, sustainable and appropriate solutions based on anticipated needs.

We must be clear on the fact that the efforts made in the next few years to increase the social participation of handicapped persons are worthy investments for Quebecers as a whole. These changes will benefit all Quebecers because a more inclusive society is a better society for everyone. The benefits of this policy will not only be in terms of the social participation of handicapped persons. They will also help to put a dent in poverty, add to the labour pool, improve the quality of life of people who experience similar problems because of age, illness or a temporary limitation, make us more open to differences, and enhance social unity.

In the long run, the number of specific anti-barrier measures will decrease as our society becomes increasingly inclusive. However, it bears pointing out that in order to respond to impairment- or disability-specific needs, there will always be specific measures available, for example, in matters of diagnosis, medical treatment, adaptation or rehabilitation, and home or community support services.

This shift also calls for a more united and equitable Québec society committed to reducing poverty and disparities in access to measures, and to progressively eliminating all existing barriers. This is a task requiring all stakeholders to innovate while stepping up their efforts aimed at more consistent, coordinated and complementary action. Society must also be more respectful of the choices and needs of handicapped persons and those of their families. What is involved here is making individualized and coordinated service provision standard practice and improving family support and accompaniment services.

Goal, nature and scope

The goal of this policy is to increase the social participation of handicapped persons within a ten-year period. The legal basis for the policy is the right to equality. There is a close connection between the idea of the right to equality and that of social participation, which is the conceptual basis of this policy. Only by observing the tangible progress achieved in the daily lives of handicapped persons, whether in terms of everyday chores, work, school or leisure, can an informed assessment be made of how the exercise of rights is faring.

The policy concerns all handicapped persons, regardless of their living environment, age, gender, impairment or disability. Granted, as a group, handicapped persons are as varied as Quebecers as a whole, but given the general nature of this document and its necessary brevity, specific kinds

of deficiencies or impairments are addressed only as the need arises. Some groups may recognize themselves in a great many of the subjects covered, while others may find that only a few of the subjects apply to them. Note that this policy is not meant to replace sector-based policies, goals or strategies, or policies designed for specific groups such as persons with physical or intellectual disabilities, or persons with pervasive development disorders or severe mental health problems. The policy is also intended to complement other government policies such as the plan to combat poverty and social exclusion and the gender equality policy.

To recap, the policy establishes cross-sectoral action priorities for the full spectrum of handicapped persons for the coming years.

It is worth mentioning that the *On Equal Terms* policy had a different focus, a theme-based approach that was innovative in its day. The final section of the document consisted of a first cross-sectoral reading of the situation that made it possible to pinpoint the same problems of inequality and service access in a number of areas. Today's policy picks up where this final chapter left off.

Note that this policy has a wider social scope. In adopting it, not only will the government make commitments, but the government will also be empowered to prompt non-governmental partners to follow suit. The government will be tasked with promoting the policy to all the players concerned across the board. This goal is in keeping with the spirit of the legislative reform in December 2004. The reform was geared to greater accountability by everyone involved in the social integration of handicapped persons, and today's policy provides a solid bench mark for implementing the Act. Furthermore, this aspect of the policy makes it a useful reference tool for drafting the independent report on implementation of the Act due for late 2009 and every five years thereafter.

Structure

Part One of this document presents the bases for the policy and the expected outcomes. It opens with the legal bases, the conceptual basis, and a comparative analysis of various legislation and policies. It then goes on to describe the target population and to provide a capsule report on the state of the social participation of handicapped persons, including the main observations about their families. It ends with the expected outcomes in terms of significant change in the lives of handicapped persons.

Part Two lays out the main challenges and priorities in terms of action. It begins by taking a look at the progress made since 1984 and the problems that persist. It then addresses the three leading challenges and the 11 action priorities arising from them:

1. For an inclusive society

- Act against prejudice and discrimination
- Act against all forms of exploitation, violence and mistreatment
- Devise barrier-free laws, policies, programs and services
- Take into account the diversity of family structures in drafting family policy
- Design accessible environments

2. For a unified and more equitable society

- Act against the poverty of handicapped persons and of their families
- Aim for adequate compensation for additional costs associated with impairments, disabilities and handicapping situations
- Increase access to and complementarity and coordination of programs and services

3. For a society that respects the choices and needs of handicapped persons and of their families

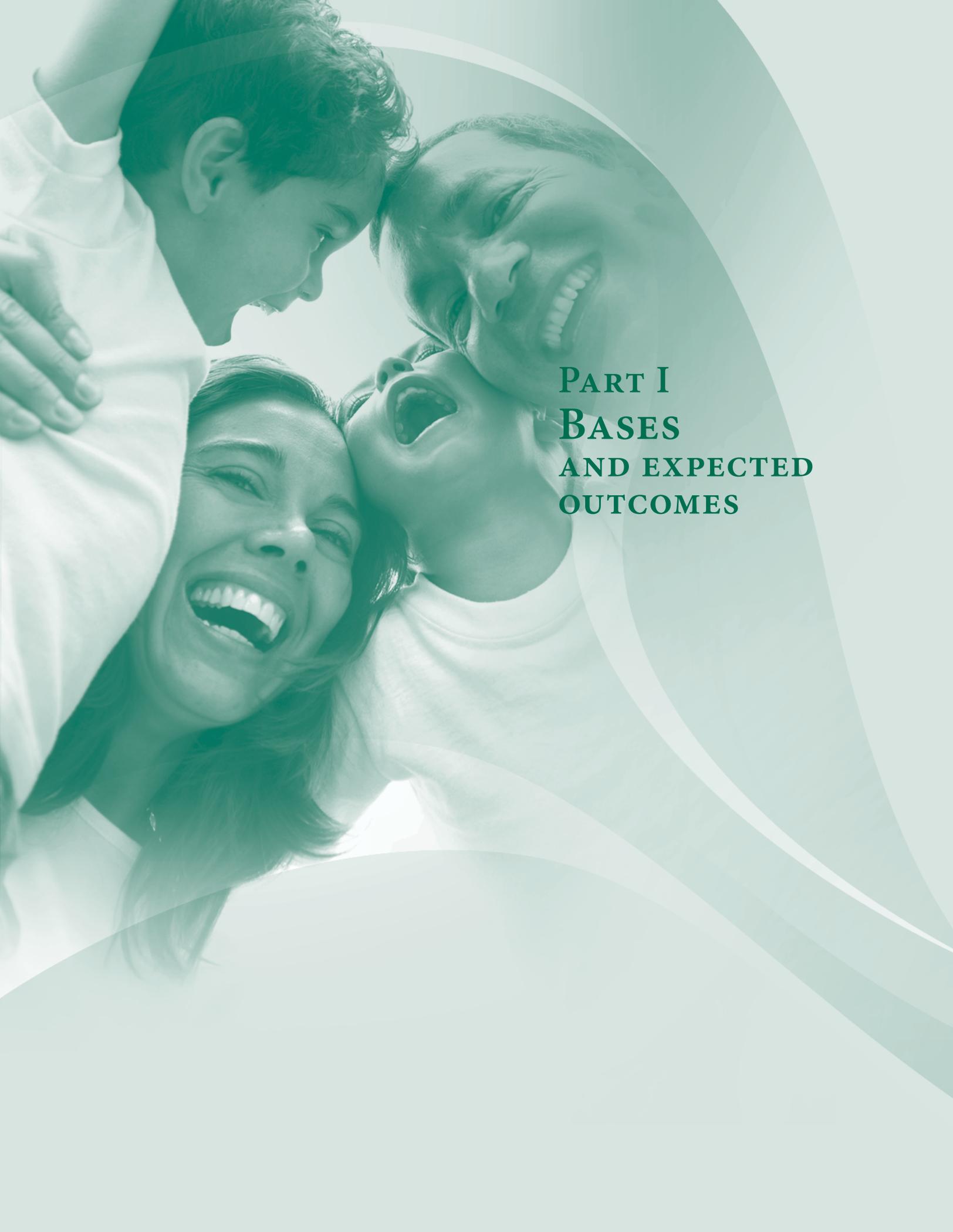
- Make individualized and coordinated service planning standard practice
- Support the exercise of family and social roles by the families of handicapped persons
- Make structured accompaniment services accessible to handicapped persons and their families.

Part Three covers policy implementation and evaluation.

A glossary of the main terms and concepts used in the document has also been provided for your convenience, along with two tables that summarize the policy. All three parts of this last section form the Appendix. In February 2008, the Office published a companion document¹ that provides additional information that details the context for the policy, describes the populations concerned, and reports on the state of their social participation in Québec society and on how this participation compares with that in other parts of the world.

1. OFFICE DES PERSONNES HANDICAPÉES DU QUÉBEC (2008). *À part entière : pour un véritable exercice du droit à l'égalité. Proposition de politique pour accroître la participation sociale des personnes handicapées. Document d'accompagnement.* The Office, 85 pp.





**PART I
BASES
AND EXPECTED
OUTCOMES**



1. BASES FOR THE POLICY

1.1 Legal bases

The policy is rooted in a certain number of ideas that are also found in law. These ideas are therefore the legal bases for the policy.

First are the ideas that stem from public law, notably, human rights, and the ideas related to human rights under civil law, in other words, notions regarding the right to equality and protection. These concepts, touched on briefly in section 1.1.1, are included for information purposes only and must not be construed as official descriptions for use in a legal setting.

The policy is also directly aligned with the provisions of the Act, covered in section 1.1.2.

1.1.1 *The right to equality and protection*

The centrepiece of this policy is the will to better ensure that the rights of handicapped persons are respected in a spirit of equality. This presupposes conditions under which they can genuinely exercise the same rights as those granted to all members of society, as well as protection of handicapped persons whose rights are threatened or denied, two interrelated prerequisites.

The educational, occupational and social integration of handicapped persons depends on their ability to exercise all their rights on fully equal

terms with their fellow citizens. This condition is explicit in the title of the Act, amended in December 2004 by adding the words “with a view to achieving social, school and workplace integration.” Here, the notion of social participation is dynamic. Handicapped persons participate fully in the life of a society by exercising their rights within that society.

Handicapped persons have the same rights as all other citizens. Section 10 of the *Québec Charter of Human Rights and Freedoms* (hereinafter referred to as the Charter) states that “every person has a right to full and equal recognition and exercise of his human rights and freedoms, without distinction, exclusion or preference based on race, colour, sex, pregnancy, sexual orientation, civil status, age except as provided by law, religion, political convictions, language, ethnic or national origin, social condition, a handicap or the use of any means to palliate a handicap” (italics and underlining added for emphasis). Section 15 of the *Canadian Charter of Rights and Freedoms* recognizes that “every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.”

However, equality in law must mean equality in fact. Having rights that cannot be exercised

in the real world is tantamount to not having any at all. It therefore becomes necessary to employ all useful means for ensuring that handicapped persons can exercise their rights. These means can be classified according to the goals that are being pursued:

- Act so that no standards have the effect of directly or indirectly preventing a handicapped person from exercising a right. At the least, this means amending, replacing or repealing standards that have such an effect. To borrow from the wording used by the Supreme Court of Canada, this also implies that standards must be designed to be “as inclusive as possible”² from the outset, so that they take into account the characteristics of every group concerned, including handicapped persons, “rather than maintaining discriminatory standards supplemented by accommodation for those who cannot meet them.”³ This is a properly inclusive approach as defined by the Court and within the meaning of this policy;
- Accommodate handicapped persons in order to empower them to assume certain roles, carry out various activities, or have access to goods and services. Concrete measures of this kind arise from what the Courts have called the “obligation of reasonable accommodation.” This obligation stems from the idea that it is not enough to treat people identically in order to treat them equally. Sometimes they must be treated differently, and “more than mere negligible effort is required to satisfy the duty to accommodate,”⁴ which is deemed “reasonable” as long as all “reasonable steps short of undue hardship” have been taken by the person responsible for discharging the duty;

- Systematically foster the exercise of rights by handicapped persons, as provided for in the Act and in this policy. A number of measures geared to this objective already exist, notably in matters of access to employment, government documents and services, and public transit. The policy is advocating introduction or improvement of a similar approach on various other fronts.

Secondly, to ensure the respect of rights, in some cases it is necessary to protect vulnerable persons whose rights are not respected or risk not being respected through mistreatment, violence or exploitation. The Charter solemnly affirms these rights for every person, including the right to life, safety, integrity, freedom and dignity. Furthermore, under section 48, any handicapped person has a right to protection against any form of exploitation. This policy therefore provides for various instruments for protecting handicapped persons, for example, by monitoring the quality of action, information or training delivered. Free and informed consent by the person concerned is required in situations of protection, unless otherwise indicated in the legislation.

To go one step further, the policy is based on the right to equality of handicapped persons without distinction, exclusion or preference on the grounds indicated in section 10 of the Charter. The policy therefore also addresses the age-, gender- and ethnic-specific problems of handicapped persons.

1.1.2 Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration

As the Foreword pointed out, this policy was adopted further to the work of the Office as prescribed under a transitional provision (section 73) of the *Act to amend the Act to secure handicapped persons in the exercise of their rights and other legislative provisions* (S.Q. 2004, c. 31), adopted in December 2004.

2 *British Columbia (Superintendent of Motor Vehicles) v. British Columbia (Council of Human Rights)*, [1999] 3 S.C.R. 868 22.

3 *Idem* 19. Statement repeated in *Council of Canadians with Disabilities v. Via Rail Canada Inc.*, [2007] SCC 15, 161.

4 *Central Okanagan School District No. 23 v. Renaud*, [1992] 2 S.C.R. 970, at page 984.

This piece of legislation overhauled the former statute (1978) and amended other laws in order to promote the full inclusion of handicapped persons within society and the development and organization of the resources and services intended for them.

This legislative review was based on a certain number of governing principles, which, in turn, have inspired this policy in large part, namely:

- Make the main civil society stakeholders more responsible for fostering the social integration of handicapped persons;
- Empower the Office to better carry out its cross-cutting role of monitoring and assessing the academic, occupational and social integration of handicapped persons;
- Take the families of handicapped persons into consideration;
- Promote the identification of solutions for reducing the disparities stemming from the cause of impairments or disabilities, age, or living environments in the plans and services available to handicapped persons and in the response to their needs;
- Promote individualized service planning;
- Foster the collaboration of advocacy organizations for handicapped persons;
- Promote standardized classification of impairments, disabilities and handicapping situations.

The policy is also based on other provisions of the Act:

- An updated definition of a handicapped person, now defined as “a person with a deficiency causing a significant and persistent

disability, who is liable to encounter barriers in performing everyday activities”;

- New policy directions (section 1.2) for enforcing the measures of the Act. These thrusts, which bring together the aims and objectives of the 1984 *On Equal Terms* policy and which, in addition, take the families of handicapped persons into account, are quoted here verbatim:

- Adopt an approach that views the handicapped person as a whole, respects individual characteristics and facilitates the increased development of capacities;
- Facilitate the autonomy of handicapped persons and their participation in individual or collective decisions that concern them and in managing the services offered to them;
- Give priority to resources and services that enable handicapped persons to remain in or return to their natural living environments;
- Facilitate the adaptation of the built environment to the needs of handicapped persons and their families without discrimination or privilege, the regional self-sufficiency of resources, and the effective linking of local, regional and Québec-wide resources;
- Foster continuing coordination for the management and complementarity of resources as well as the permanence and maximum integration of services;
- Achieve a decent quality of life for handicapped persons and their families, full social integration of handicapped persons and maximum protection against risk factors for impairment.

1.2 Target population

The policy will spell positive change for all Quebecers, but in particular for handicapped persons within the meaning of the Act. The above definition applies to men and women alike, whether children, adults or seniors, whose impairments result in significant and persistent disability (motor, intellectual, speech, visual, hearing or other sensory, organic, pervasive developmental disorder or severe mental health problem). Note that the definition provides for the inclusion of persons whose significant disabilities are episodic or cyclical.

The fact of being a person “liable to encounter barriers in performing everyday activities” suggests that not all persons with impairments and deficiencies necessarily encounter these barriers. However, within the meaning of the Act, they are nonetheless considered handicapped persons. The measures designed to make up for disabilities and to facilitate the performance of everyday activities, for example, aids or adaptations, may change, become unavailable, or no longer be what is required. The existence of impairments or deficiencies means that at some future point these persons may find themselves in a handicapping situation and, therefore, become liable to be confronted with barriers in performing everyday activities.

1.3 An exhaustive and avant-garde policy

This policy must, within a ten-year time-frame, make it possible for further progress to be made so that handicapped persons can truly exercise their rights, in keeping with and in support of the legal bases referred to previously. To achieve this, the policy must serve as a template for government action and that of other stakeholders, with a view to identifiable gains in terms of the social participation of handicapped persons.

The policy describes the main challenges that must be given special attention and establishes action priorities which are goals to be shared

and implemented so that the main barriers to social participation are dealt with effectively. These priorities call for substantial shifts in intervention methods and for inter-sectoral initiatives. As indicated previously, this policy, whose scope is inter-sectoral and comprehensive, comes with an implementation plan comprising objectives that cover areas of action that are more specific.

The policy, like all other modern policies of its kind, must identify the outcomes that Québec wishes to achieve within the prescribed timeframe. These outcomes articulate the nature and thrust of expected changes in the social participation and living conditions of handicapped persons.

Québec’s legislative choices in recent years, as well as this policy, rank favourably against those of other states and jurisdictions because of their innovativeness or positive short- or medium-term potential for the social integration of handicapped persons.

The Act contains numerous measures designed to improve the integration of handicapped persons, e.g. employment measures, annual action plans, access to public documents and services, transportation, right to receive information, obligation for public bodies to implement recommendations, government procurement, and an independent five-year progress report on implementation of the Act. The impact clause, under which the minister responsible for enforcement of the Act must be consulted when the measures that could have a significant impact on handicapped persons are created, is particularly powerful because it makes proactivity possible, upstream of public initiatives.

Legislation in New Brunswick, British Columbia, the United States and France contains only some of the measures of the Québec Act. In terms of the potential for a positive short- and medium-term impact on the integration of handicapped persons, Québec is at the forefront when compared with Ontario, for example, where legislation does not prescribe a minimum timeline for implementing

the main measures but instead, says that measures in general must be produced and implemented by January 1, 2025.

The policies and strategies of five countries were also analyzed briefly (*National Disability Policy, Healthy People* – United States; *Improving the Life Chances of Disabled People* – England; *The Commonwealth Disability Strategy* – Australia; *The New Zealand Disability Strategy* – New Zealand; *Integrated National Disability Strategy* – South Africa; *Equal Opportunity for People with Disabilities. A European Action Plan* – European Community; and *From Patient to Citizen: A National Action Plan for Disability Policy* – Sweden). These countries were chosen because of the similarity of their culture and parliamentary system with that of Québec. Whether in the United States, Australia, South Africa, England, or European Union countries, legislative measures to eliminate or reduce barriers to greater social participation by handicapped persons are implemented through a policy or comprehensive strategy, or are built into more specific legislation. There is a clear trend throughout the world, and this policy puts Québec in the mainstream.

The underpinning of many policies for handicapped persons around the world is social participation. Inspired by forward-looking policies that originated in Northern Europe, this approach centred on social participation is, in turn, based on the principle of equality. In the policies analyzed, social participation outcomes are often measured using indicators from population surveys, and Québec is innovative in this respect.

It also bears mentioning that this policy dovetails in many ways with the spirit and letter of the United Nations *Convention on the Rights of Persons with Disabilities* adopted in December 2006. Even though Canada had not yet ratified the Convention, it was used as an international marker in drafting the policy.

Clearly, the Act and the policy are in the vanguard.

1.4 A new way of conceptualizing social participation

The policy is organized around a new way of conceptualizing social participation, the Disability Creation Process (DCP). This approach, chosen by the Office and its partners, makes Québec a leader in the field.

As defined by DCP, social participation, the result of the multi-tiered interaction between a person's characteristics and the elements of that person's physical and social environment, is the full realization of "life habits" (nutrition, transportation, mobility, housing, communication, and exercise of social roles, namely, study, work, leisure, political involvement, membership in clubs or community groups). Full social participation also means that handicapped persons should be able to live with their families or within their community and interact with the people in these environments. This approach places strong emphasis on respecting the choices of handicapped persons and considers their sociocultural identity an operative factor. It pays special attention to the quality of the conditions governing social participation so as to ensure equality with fellow citizens.

According to this model, a person can be a social participant in one area of his or her life, leisure activities, for example, but have a handicapping situation in the workplace. We therefore cannot view social participation or handicapping situations as static conditions that apply to every facet of a person's life throughout his or her lifetime. The situation can change in the course of a lifetime and vary according to the activities or social roles concerned. The action called for must take all of this into account. Lastly, the situation in one part of a person's life influences other aspects of that person's situation. For example, limitations in terms of transportation infringe on the ability to hold down a job or take part in training activities.

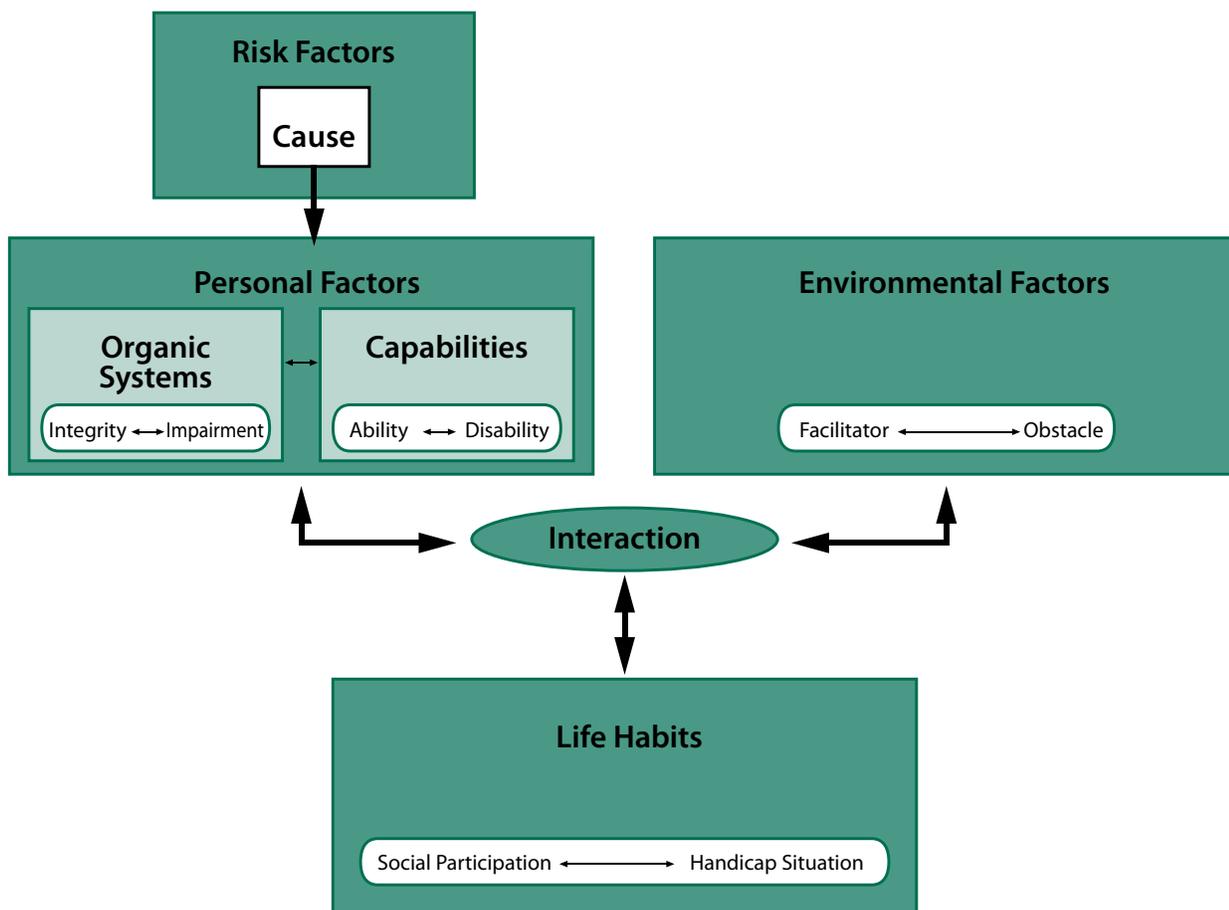
The purpose of this model is complete consideration of a person's potential and strengths. It steers clear of exclusively negative terminology

in favour of more neutral terms, such as organic systems, capabilities, environmental factors and life habits.⁵ Assessment of a person's situation makes it possible to pinpoint his or her potential for each of the elements examined. For example, the integrity of certain organic systems can be determined, abilities identified, facilitating factors of the environment inventoried, and a conclusion made about social participation. The model also enables impairments and disabilities to be evaluated, along with the barriers within the environment, while identifying the prevailing circumstances in a handicapping situation. This approach yields assessments that are more nuanced and complete, not only of individuals, but of handicapped persons as a whole. These properties, coupled with significant conceptual advances over other classifications, make DCP a model of choice.

⁵ The definitions of these terms are presented in the Appendix.

DIAGRAM

Québec classification of the Disability Creation Process (DCP):
Model that explains the causes and consequences of disease, trauma
or other disruptions in a person's integrity or development (SCCIDH 1998)





2. THE SITUATION OF HANDICAPPED PERSONS AND OF THEIR FAMILIES IN QUÉBEC

This policy is aimed at significant change in the lives of handicapped persons. But what does exercise of their rights mean in the real world? How effective is it? One of the best ways of answering these questions is to see whether handicapped persons participate in Québec society as their fellow citizens do, in other words, whether they can go about their daily business and carry out their roles within the community at large.

The following snapshot of handicapped persons and their families is primarily based on the latest and most reliable data, sourced from various Québec government departments, Statistics Canada surveys on Quebecers, and the Canadian census. According to the figures from 2006, Québec has more than 750,000 handicapped persons, that is, 10% of the total population of Québec.

2.1 Age- and gender-dependent incidence

There are more handicapped women than men in the 15-year-old-and-over category. This gap widens as of age 65 and spikes in the 75 year-old-and-over cohort. However, in people under age 15, the opposite occurs (more males than females).

The proportion of handicapped persons increases with age, which, according to the latest statistics, rises dramatically from 7% for 15- to 64-year-olds to 28% for people 65 years of age and older. Given the demographic forecasts for population aging in Québec, it is reasonable to expect that the number of handicapped persons will increase in the next few decades. This will necessarily have an impact on the organization and funding of services to them. However, there is no foolproof way of determining the extent of this impact. Some experts predict that there will be strong pressure on services as a

whole, while others, who reject the most pessimistic scenarios, argue that the better health enjoyed by today's seniors and the technological advances of our society will offset the adverse effects.

Be that as it may, this policy considers that elderly handicapped persons deserve special attention, whether their impairments are age-induced or not. It also insists on the importance for Québec society to find sustainable solutions, notably for service organization and funding, in preparation for a future in which the number of handicapped seniors is bound to increase.

2.2 Families grappling with multiple difficulties

The figures paint a grim picture of the difficulties of families that include a handicapped person, which account for 20% of all Québec families or, childless couples excluded, 12%. One of the main findings is the frequency of situations in which more than one handicapped person is part of the same family, especially in cases of families with handicapped children. In one third of the families that contain a handicapped child who is a dependant, there is also another handicapped person, in most cases, a parent. Also, in half of the families that contain a handicapped child of the age of majority there is also another handicapped person, again, in an overwhelming majority of cases, a parent.

In light of these figures, the tip of the proverbial iceberg, it is safe to assume that the effect on families is major. Where these multiple occurrences exist, there is likely to be broken families and poverty. The situation is exacerbated by the fact that families are on the front line as caregivers to their loved ones. Given this fact, this policy focuses a great deal of attention on families that contain a handicapped person or persons.

2.3 Underprivileged overall

Even in this day and age, handicapped persons as a group are poorer, less educated, and in poorer health than their fellow citizens, and are socially isolated. Their low level of schooling may be one of the reasons for their poverty. Anecdotal and scientific evidence alike shows that handicapped persons are more likely to live below the poverty line. The situation of handicapped women is particularly troubling because, being female, they are statistically more likely to be poor than men.

These social and economic disadvantages take their toll on the physical and mental health of handicapped persons. Certain chronic health problems, such as arthritis, hypertension, diabetes and heart disease, are more common among handicapped persons, who are also more prone to smoke and have a sedentary lifestyle. These risk factors, combined with difficult socioeconomic conditions, are known to contribute to the development of many chronic diseases.

All of this is compelling proof of why, given their socioeconomic profile and lower social participation, handicapped persons could develop more health problems than their fellow citizens who are not handicapped. In turn, these health problems hinder their social participation, in a vicious circle of factors.

2.4 Social participation: A daily challenge for handicapped persons

For many handicapped persons in Québec, social participation is nothing less than a daily challenge, even in the 21st century. For many of them, daily living activities such as getting meals, doing housework, going to appointments, running errands, balancing their cheque-book, or tending to their personal hygiene, are very challenging. Being properly housed, communicating, and getting from point A to point B are other activities that many handicapped persons can find very demanding.

However, in recent years, certain gains have been made, notably in the integration of handicapped children within early childhood educational child-care and within regular classrooms. Strides have also been made in terms of the ballot box and social involvement. However, Québec, with mainstreaming rates that have not budged for several years, still has a long way to go. In addition, there is a yawning gap that persists between handicapped persons and other Quebecers in the workplace, which translates into a jobless rate twice that of persons who are not handicapped.

Certain groups of handicapped persons have more trouble than some of their peers. Available data indicate that more women than men need help with their daily activities and report that their needs in this respect are not being met. Even though they now have a higher level of education than men, fewer of them have jobs. It is also well known that the severity of an impairment influences social participation, regardless of type. The same holds true for multiple impairments. The figures point tellingly to the difficulties experienced by persons with intellectual impairments, pervasive development disorders or severe mental health problems, particularly with regard to school attendance and labour market participation. There is less literature on the situation of other groups, such as Aboriginal people or members of ethnocultural communities. However, there is reason to believe that they too experience difficulties in terms of social participation. This policy, which cuts across all these groups, dwells more extensively on Native populations and members of ethnocultural communities.

3. EXPECTED OUTCOMES OF THE POLICY: REAL CHANGES IN THE LIVES OF HANDICAPPED PERSONS AND OF THEIR FAMILIES

This policy identifies the changes to be achieved in the lives of handicapped persons within the next ten years, based on demographic, economic and social projections. These goals are expressed through a set of expected outcomes that are legally and conceptually founded and grounded in the most recent and reliable data on the situation of handicapped persons. In addition to providing a clear picture of the targeted changes, the inclusion of expected

outcomes also creates a framework for evaluating the policy, an approach used by an ever-growing number of modern public policies.

The ultimate goal is significant improvement of the living conditions of handicapped persons, a full response to their fundamental needs, and their parity with other citizens in the exercise of their social roles.

Expected outcomes

Towards significant improvement of the living conditions of handicapped persons

- Improve the income of handicapped persons.
- Improve the health of handicapped persons.
- Improve the educational level of handicapped persons.
- Reduce the social isolation of handicapped persons.

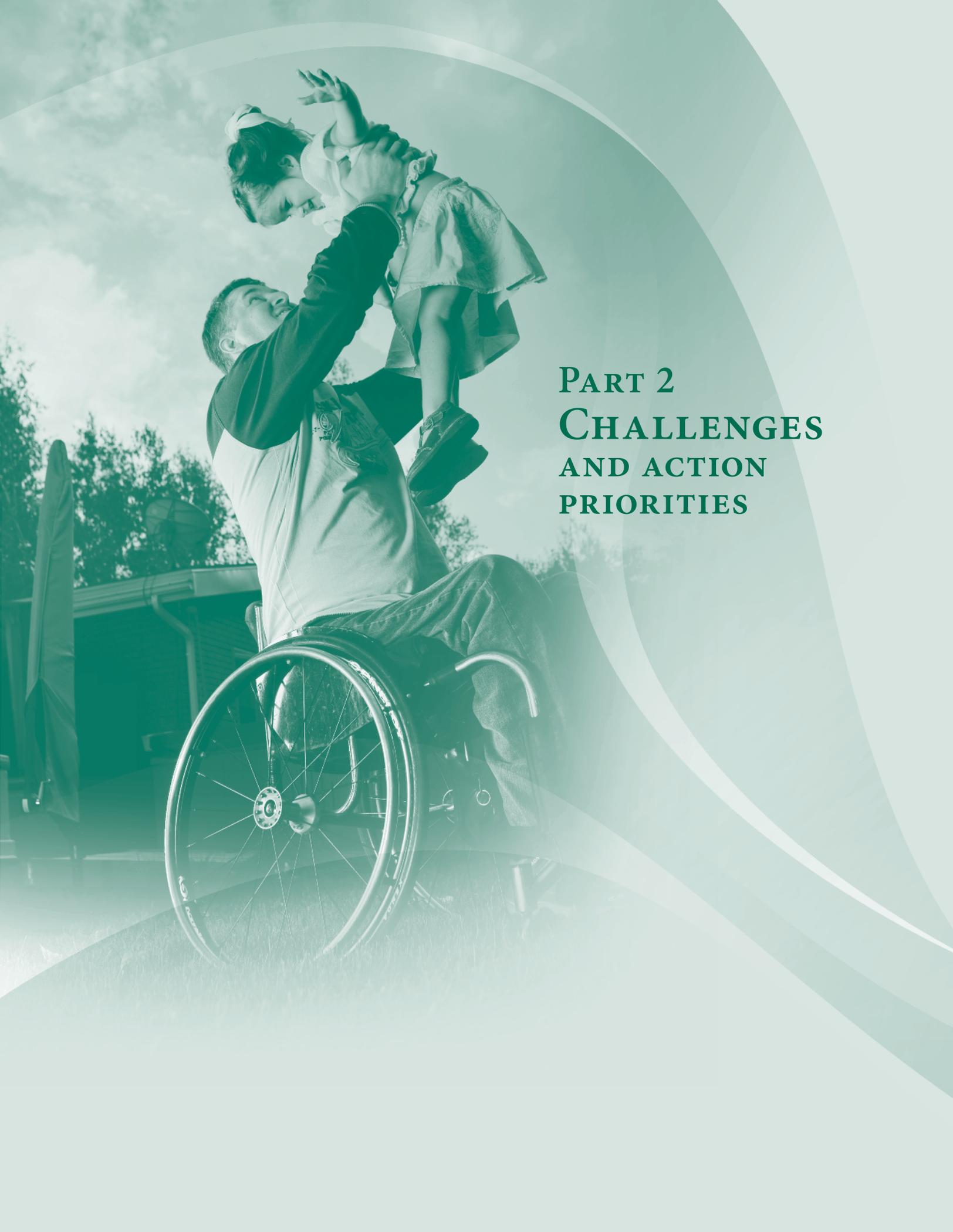
Towards a full response to the basic needs of handicapped persons

- Offer handicapped persons the possibility of fully carrying out the activities that allow them to live at home.
- Offer handicapped persons the possibility of being housed adequately according to their specific needs, in a place of their choosing.
- Offer handicapped persons the possibility of expressing themselves and communicating adequately with those around them, whatever means of communication are used.
- Offer handicapped persons the possibility of being mobile without added accessibility, time or cost constraints, no matter the place or the means used.

Towards parity between handicapped persons and other citizens in the exercise of social roles

- Increase the participation of handicapped children in educational daycare services and in school environments.
- Increase the participation of handicapped students at all levels of basic and continuing education.
- Increase the participation of handicapped persons in the workplace, without discrimination.
- Increase the participation of handicapped persons in recreational, sports, tourism and cultural activities.
- Increase the civic participation of handicapped persons in their community under conditions equivalent to those of other citizens.



A photograph of a man in a wheelchair holding a baby, set against a background of a house and trees. The image is overlaid with a large, semi-transparent teal circle. The man is wearing a light-colored t-shirt and dark pants. The baby is wearing a light-colored dress and shoes. The text is positioned to the right of the man.

PART 2
CHALLENGES
AND ACTION
PRIORITIES



4. COMMON BASES FOR ACTION

To achieve real results in terms of social participation and to significantly improve the living conditions of handicapped persons, there must be a common basis for action. We must all be on the same page when it comes to the challenges to be addressed and the priority action to take in the next decade.

4.1 Progress and persistent problems

Substantial gains

The past 30 years have put the issue of the social integration of handicapped persons on the front burner, and their entitlement to the same rights as other persons is undisputed. Their more widespread involvement in all areas of endeavour attests to increasing openness within Québec society. The commitment of advocacy groups and ongoing efforts to raise awareness has greatly contributed to these changes. The past three decades have also seen government creation of a wide array of services that are public, universal and free. Specific laws, policies and programs have been adopted, and efforts made towards more coherent action and customized responses to needs, due in particular to mobilization further to the *On Equal Terms* policy. In addition, there has been a knowledge explosion, not only in terms of the availability of data, but also in terms of research.

Problems that persist

Despite these gains, the everyday lives of most handicapped persons and of their families remain

very precarious, their social participation remains limited, and adequate responses to their needs remain hindered by barriers that continue to exist. Formal recognition of their rights and their higher level of activity within society notwithstanding, handicapped persons still experience exclusion and discrimination. Stereotypes persist and decision-makers and the public in general are, by and large, ignorant of the potential of handicapped persons, many of whom are susceptible to exploitation, violence and mistreatment. In many cases, families are exhausted and their needs and expectations are immense.

Service organization is plagued by problems of access, coordination and coherence, and there are gaping disparities stemming from the cause of a person's impairment, a person's age, or a person's living environment, especially in outlying regions. Lack of resources compromises responses to the fundamental needs of handicapped persons and of families, who are given little support and guidance in their attempts to access services. Furthermore, handicapped persons are not systematically factored into society's core economic and social policies, its infrastructure, and its high technology, notably in the area of communications.

Very often, innovation is required in order to produce responses tailored to needs that are constantly changing in pace with Québec society, cases in point being the greying of the population, more immigration and ethnocultural diversity, the highly mutable family, modernization of the State, and regionalization.

4.2 Guidelines for action

These changes as a whole call for a different approach to the action taken with regard to handicapped persons and their families. The challenges identified and the proposed responses deal with the main barriers to the social participation of handicapped persons and with their living conditions, and, therefore, are consistent with the aims and objectives enshrined in section 1.2 of the Act, which are intended as a set of guidelines for society's action and approaches. These aims and objectives, based on fundamental values, namely, human dignity, freedom, equality, eradication of discrimination, solidarity and equity, are found in a number of Canada's and Québec's laws and policies and in those of other jurisdictions, as well as in international instruments for protecting human rights and more specific instruments for handicapped persons, such as the United Nations *Convention on the Rights of Persons with Disabilities*. These values must be upheld. Furthermore, there must be a common and clear understanding of them if they are to work as guidelines for action that produce real results.⁶

Acting according to these aims and objectives involves recognizing and respecting the fact that every handicapped person is unique. Ultimately, what handicapped persons are seeking is control of their lives and power to do so (empowerment). Any course of action must take the entire person into account. This means focusing on their abilities, acknowledging their expertise and that of their families and of the organizations that represent them, and ensuring their participation in individual and group decisions that concern them.

Consultation of handicapped persons and advocacy organizations and their effective participation are crucial to designing and evaluating the policies, programs, services, training and research intended for them. This requires sufficient support and resources that take into account any additional participation-related costs. Enhanced empowerment, which

must be transposed to real-life action, encompasses everything that supports the contribution of citizens to the greater community, democratically and for the common good.

4.3 Challenges to meet and priorities to share

Three major challenges emerge from this overview of the situation, and even though they are distinct and presented as such, they are best understood as forming an interrelated whole. Furthermore, it is fitting that families and gender equality are uppermost concerns. Only by taking up these challenges will tangible results be achieved. The efforts to deploy in the next few years are invaluable investments for all Quebecers and the resulting changes will benefit every citizen because a more inclusive society is a better society for all. These investments will help to put a dent in poverty, add to the labour pool, improve the quality of life of people who experience similar problems because of age, illness or a temporary limitation, make us more open to differences, and enhance social solidarity.

4.3.1 Challenges to meet

An inclusive society

In recent years, much has been made of adapting the social and physical environment in order to support the social integration of handicapped persons. This has led to specific policies, measures or initiatives to make existing environments, facilities or equipment accessible, even though originally they were not necessarily meant to meet the needs of handicapped persons, e.g. adapted housing or vehicles. Clearly, these measures are simply not enough, to say nothing of the fact that adaptation is much more costly for individuals and the public purse than built-in accessibility.

The message is that we must do things differently and step up inclusivity. We must design the physical and social environment to take the needs

6 See the Appendix for a presentation of these values.

of every member of society into account, including handicapped persons and their families, so that adaptation or special action after the fact is not required. It is no longer up to people to adjust to environments that were not designed for them. Instead, society must respect the diversity of its citizens. This paradigm shift therefore involves doing what has to be done to ensure that all citizens participate in the life of our society, see themselves as part of it, contribute to it, and reap the benefits thereof.

This approach is similar to that of “universal design”⁷ as defined in the *Convention on the Rights of Persons with Disabilities* or to that of a broader concept, “universal accessibility,” which is becoming the expression favoured by practitioners.⁸ The approach does not involve the dismantling of adaptive measures, which will always be considered valid and complementary solutions because there will always be special situations that require customized responses. Greater inclusivity also supposes that handicapped persons will no longer be considered separate from their social environment. They are full-fledged members of the society that they help to develop and shape. An inclusive society therefore acknowledges the contribution of handicapped persons in every respect and uses this contribution for its development.

This conceptual shift also includes major changes in approaches towards families. Handicapped persons are part of families. They develop within them, form

new ones and are transformed as the family itself is restyled or recast. Greater inclusivity presupposes recognition of the crucial role that families play for all human beings, not only for individuals, but as a social construct, the nuclear family, which is the first community in which human beings live and, therefore, one of the cornerstones of society. Former approaches, which tended to view families as separate and distinct from its members and, in the case of handicapped persons, as external resources, are no longer valid.

A unified and more equitable society

With inclusivity comes another challenge—solidarity and equity towards handicapped persons and their families. Simply put, a unified and more equitable society sees to it that handicapped persons and their families have an adequate lifestyle. The income of handicapped persons and of their families is demonstrably below that of the other members of society. To make matters worse, these families have extra expenses that are not necessarily covered by current plans or measures. This is one of the cogs in the relentless wheel of poverty.

A unified and more equitable society must therefore make up for shortfalls in the income of handicapped persons and of their families and provide adequate compensation for the extra financial burden they bear. The services and equipment required for them to exercise their rights and to tend to their family and social responsibilities on an even playing field with the other members of society must be provided. In the past, plans, programs and services for handicapped persons were cobbled together in response to specific problems and there was no deliberate attempt at overall coherence or seamlessness. The current service infrastructure is made up of various cause-based disability plans. In addition to co-existing with the general social safety system intended for all citizens, including handicapped Quebecers whose cause of impairment is not covered by disability-specific plans, each of these systems developed separately. The resulting disparities only serve to exacerbate age- and region-related disparities.

7 “Universal design means the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. Universal design shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.” *Convention on the Rights of Persons with Disabilities*, article 2. General Assembly of the United Nations, A/RES/61/106.

8 “The idea behind universal accessibility is to build a world in which everyone, including persons with functional limitations, can live freely and safely, have access to the same places, services and activities, and have the same experiences at the same time and in the same way.” [Translation] COPHAN, Association des groupes d’intervention en défense de droits en santé mentale du Québec, Association du Québec pour l’intégration sociale, AQRIPH, *Pour un Québec inclusif*, document tabled with the Office during draft policy consultations, October 2007, p. 5.

Certain programs suffer from chronic and persistent underfunding or lack of professional resources, leading to long waiting lists, insufficient coordination with other resources within the community, or organizational or administrative defects. There is need to improve and streamline the current organization of services to handicapped persons and their families so that they have better access to services and other support measures. Work also needs to be done to improve and simplify equity among the various systems and programs.

A society that respects the choices and needs of handicapped persons and of their families

What is involved here is to translate the will of the government to make its services citizen-centred into measures that are right for handicapped persons and for their families. Enhancing personal independence, while preserving the family environment as the primary setting for integration, also means preventing institutionalization and the resulting costs. Achieving equity entails meeting the needs of handicapped persons and of their families in such a way as to enable them to make real choices and be in control of their lives. The person as a whole must be considered and his or her individuality and uniqueness must be respected. Support to handicapped persons necessarily requires that every dimension of their situation is considered—their development, aptitudes, history, plans for the future, and the environmental barriers in their way. They must not be viewed only from the angle of their disabilities and needs, but from a vantage point that provides a view of their strengths and skills.

Similarly, the contribution and skills proper to families must be acknowledged and supported because family members have in-depth knowledge of each other. Every family is unique and has its own history, dynamics, values and expectations. These defining characteristics must be respected. The critical contribution of family members must be recognized and they must be given more support in the exercise of their family, occupational and social responsibilities. Families are all too often considered free

resources whose availability is automatically assumed and who are offered only ad-hoc measures, and sometimes only in moments of crisis. These families, forever on the brink of collapse, cannot properly fulfil their family, social and occupational obligations under these conditions.

This, of course, presupposes changes in the way that services to handicapped persons and to their families are planned and organized. In turn, these changes imply the use of a personalized approach that takes every facet of the situation of handicapped persons into account, respects their life choices, and is geared towards their empowerment.

Service organization must therefore be in keeping with the expectations and aspirations of handicapped persons and be such as to enable them to choose the means and the services best suited to their needs and goals. It must also respond to the needs of family members, take their choices into account, and give them the support they need to engage in daily life and carry out their role within the family and society at large, notably by helping them to balance their responsibilities within the family and in the workplace. It may happen that the choices of the handicapped person and those of the family do not coincide. In such cases, unless indicated otherwise in the relevant legislation, the choices of the handicapped person prevail.

4.3.2 Priorities to share

This policy proposes eleven priorities in terms of action, in conjunction with the National Strategy for Labour Market Integration and Maintenance of Handicapped Persons provided for under section 63 of the Act. These priorities are intended as goals to be pursued in a broad-based assault against the barriers to the social participation of handicapped persons.

For an inclusive society, the priorities are to:

- Act against prejudice and discrimination
- Act against all forms of exploitation, violence and mistreatment

Government policy for increasing the social participation of handicapped persons

- Devise barrier-free laws, policies, programs and services
- Take into account the diversity of family structures in drafting family policy
- Design accessible environments.

For a unified and more equitable society, the priorities are to:

- Act against the poverty of handicapped persons and their families
- Aim for adequate compensation for additional costs associated with impairments, disabilities and handicapping situations
- Increase access to, complementarity and coordination of programs and services.

For a society that respects the choices and needs of handicapped persons and of their families, the priorities are to:

- Make individualized and coordinated service planning standard practice
- Support the exercise of family and social roles by the families of handicapped persons
- Make structured accompaniment services accessible to handicapped persons and their families.



5. AN INCLUSIVE SOCIETY

We can never overstate the fact that all citizens benefit from efforts to make society more inclusive. Making Québec society inclusive hinges on action on different levels. Since this challenge is closely related to the respect of human rights, the first two priorities deal with situations that contravene these rights, hence, the need to act against prejudice, discrimination, and all forms of exploitation, violence and mistreatment. Three other priorities for achieving inclusivity are to devise barrier-free laws, policies, programs and services; take into account the diversity of family structures in drafting family policy; and design accessible environments.

5.1 Act against prejudice and discrimination

To act with a view to inclusivity is to act in order to prevent situations of prejudice and discrimination. A society bereft of a comprehensive vision of the diversity of its citizens and relatively unaware of the potential of handicapped persons is at high risk for reinforcing stereotypes and for discriminating against many of these persons. It is imperative that, from the outset, the various stakeholders establish measures for enhancing public awareness and for nipping prejudice and discrimination in the bud.

The difficulties arising from a combination of characteristics that occur in situations of discrimination, what some experts call “intersectional discrimination,” warrant particular attention. Means for preventing prejudice and discrimination include: a) public awareness; b) civic education for young people and adults; c) awareness-raising and training for anyone in direct contact with the public; d) accommodation measures and promotion of inclusivity; e) factoring in of cultural barriers in accommodation measures for handicapped persons from ethnocultural communities; and f) documentation of the experiences of handicapped persons from First Nations communities.

a) *Public awareness*

Prevention of prejudice and situations of discrimination hinges on a better understanding of handicapped persons, of their potential, and of their needs, and on an adequate grasp of the conditions conducive to their participation in life within society. Lack of knowledge about handicapped persons and the resulting prejudice is expressed as pity, condescension, uneasiness or puzzlement. Prejudice worsens in the presence of other possible reasons for discrimination, for example, gender, age, religion, ethnic or national origin, Aboriginal status, or sexual orientation. Whether these prejudices come from outside the person or from the person’s frequently negative self-image, the outcome is the same, namely, social exclusion and perhaps even discrimination. Public and media awareness is a powerful agent of change in favour of full recognition of the potential of handicapped persons and of their ability to contribute to Québec society, especially in the workplace. Teaching awareness to the children in daycare, preschool and first grade is a worthwhile initiative, as is on-the-job awareness training.

b) *Civic education for young people and adults*

Another tool available to society is civic education for young people and adults. The curricula for preschool, elementary and secondary school, college, university and continuing education are of primary importance in creating public awareness and preparing all members of our society to interact positively with handicapped persons by taking their rights, needs and social integration into account. By making information and training concerning handicapped persons, their features, their potential and their needs a part of education programs, many of the prejudices and situations of discrimination stemming from ignorance will be prevented.

One way of making this happen has to do with the Office's new responsibilities under the Act. Section 25e.1 states that the Office must "promote, in the training programs of university, college and secondary level educational institutions and organizations responsible for vocational training, the inclusion of elements dealing with the adaptation of interventions and services for handicapped persons" and "promote the creation of information and training programs designed to foster a better understanding of handicapped persons, their needs and the conditions conducive to their integration into and participation in community life, or develop such programs, in cooperation with advocacy and service organizations" (s. 26 g.1).

This action by the Office, along with other sectoral and intersectoral initiatives, such as citizenship education programs in childcare and in various parts of the school system, could provide the impetus for the progressive inclusion of disability-related content in curricula and to adaptation of services and interventions. In addition to preventing potential situations of prejudice and discrimination, these initiatives would have a positive effect on services.

c) *Awareness-raising and training for anyone in direct contact with the public*

Anyone who works directly with the public is on the front line in terms of the reception of handicapped persons and their access to basic services. In recent years, government departments and agencies have emphasized the importance of offering quality customer services to all citizens. Despite ongoing progress, there still are misunderstandings that could be avoided if public servants and private sector employees and community organization staff were more sensitive to the issue of handicapped persons. Training is the key in this respect.

d) *Accommodation measures and promotion of inclusivity*

Accommodation measures are a natural outgrowth of the right to equality applied to prevent situations of discrimination. As pointed out earlier in this document, adjustments after the fact are very costly without

being considered "undue hardship" by the courts. These efforts can be avoided or substantially pared down if the needs of handicapped persons are taken into account from the beginning. Promotion of exclusivity can therefore make it possible to circumvent these difficulties, while at the same time having a positive impact for handicapped persons and, more often than not, for the public as a whole.

e) *Factoring in of cultural barriers in accommodation measures for handicapped persons from ethnocultural communities*

Cultural barriers and poor language acquisition are some of the obstacles faced by handicapped persons and their families from various ethnocultural communities. Given the problems they have in making themselves understood and in getting the information they need, it is sometimes impossible for these people to access the required services and resources at par with other citizens. Furthermore, francization programs either do not exist or are not adapted to the different types of disabilities. The solution is innovation with a view to second-language acquisition in Braille or sign-language, or francization programs for persons with intellectual disabilities.

Cultural differences trigger other barriers, whether in terms of service access or understanding a foreign system. This is why these cultural differences and dissimilar value systems must be considered because they may impinge on the way assistance is offered or received.

f) *Documentation of the experiences of handicapped persons from First Nations communities*

There is very little recent literature on the situation of handicapped persons from First Nations communities in Québec because most available data are Canadian in provenance. However, the figures show that handicapped persons from First Nations communities may be marginalized and discriminated against. This is why an accurate portrait of handicapped persons from Québec's Native communities is crucial if we are to respond to their needs in the best way possible.

5.2 Act against all forms of exploitation, violence and mistreatment

Respecting human rights and freedoms entails paying particular attention to handicapped persons in situations of vulnerability who must be given the required protection against any attacks on their integrity and safety as other citizens. Unless otherwise stipulated, any protective action must occur with the free and informed consent of the individual. Measures should also be established to prevent all forms of negligence, exploitation, physical, psychological, verbal or financial abuse or violence of any kind, including sexual, spousal or family violence. Women, children and the elderly are the most likely to be victims, along with persons with intellectual disabilities, pervasive developmental disorders or serious mental health problems. The perpetrators may be family members, acquaintances, caregivers or strangers. Exploitation, violence and mistreatment can occur almost anywhere—within the home (spousal or family violence), in caregiving situations or in public living environments such as residences, shelters or other similar institutions.

While information about the extent and nature of these situations and of the consequences for the victims is scarce, a certain number of contributing factors have been identified: specific disability types and disability severity, dependency on others for everyday activities, lack of self-protection and defence skills, unawareness or trivialization of the unacceptability of the abuse or violence, difficulty in communicating with the outside world, lack of personal relationships outside the immediate circle, psychological distress, social isolation, low level of education, insufficient sexual education, prejudice against and attitudes towards handicapped persons, and difficult socio-economic circumstances.

Given current knowledge or lack thereof, the general means for combating all forms of exploitation, violence and mistreatment are the following: a) informing and training handicapped persons and their families and friends; b) designing action

tailored to the everyday lives of handicapped persons and adapting it accordingly; c) monitoring the quality of intervention in public living environments such as residences, shelters or other similar institutions and in private caregiving situations; and d) implementation and promotion of the recourse provided under existing legislative provisions.

a) *Informing and training handicapped persons and their families and significant others*

To prevent situations of exploitation, violence and mistreatment, handicapped persons, their families and their significant others must be better equipped to avoid these circumstances, recognize them and report them. This can be done through information and training. Emphasis must be placed on the persons most at risk, notably, women, children and seniors, as well as people who need assistance with their everyday activities, those in institutional settings, and those with intellectual disabilities, pervasive development disorders or serious mental health problems.

b) *Designing action tailored to the everyday lives of handicapped persons and adapting it accordingly*

In order to intervene properly and effectively, health and social service workers, police forces and the legal community must know more about the daily lives of handicapped persons, especially, their particularities and their specific areas of vulnerability. One answer is awareness and training activities on the forms of violence to which these people are exposed. Openness to diversity could also be covered. In addition, people who work within the health and social services network should be better equipped to detect potentially violent situations before they occur. Coordinated and synchronized action must also be developed in order to better identify situations of exploitation, violence and mistreatment and to zero in on the ways of meeting the specific needs of handicapped persons in these circumstances, while ensuring their access to services and resources that are an adequate response to their needs. A preferred means of action is for the victims or potential victims to choose an individual or organization to accompany them.

c) *Monitoring the quality of intervention in public living environments such as residences, shelters or other similar institutions and in private caregiving situations*

Current efforts to supervise the living environments of handicapped persons through various quality control mechanisms should be continued. These means include scrutiny at the licensing or private-sector or public-sector certification stage. Handicapped persons, especially those with reduced autonomy, are at risk, hence the need for measures to control the quality of the services offered them and to monitor the safety of their environment.

d) *Implementation and promotion of recourse provided under existing legislative provisions*

Québec has a number of legislative instruments to prevent the exploitation of persons in situations of vulnerability or, barring the possibility of prevention, to put a stop to the situations that compromise their safety, with the free consent of the victims. As pointed out previously, section 48 of the *Québec Charter of Human Rights and Freedoms* specifies that “every aged person and every handicapped person has a right to protection against any form of exploitation” and that “such a person also has a right to the protection and security that must be provided to him by his family or the persons acting in their stead.” What the Charter is in fact saying is that elderly persons or handicapped persons may need protection against exploitation insofar as they are vulnerable psychologically, socially, economically, and culturally, or depend on others for meeting their basic needs. The purpose of this protection is to prohibit all forms of monetary, material, physical, psychological, social or moral exploitation. The Charter, an invaluable instrument for protecting the interests of persons in situations of vulnerability, makes it possible for complaints to be filed with the Commission des droits de la personne et des droits de la jeunesse in order to have these incidents cease and to receive compensation for damages.

A new legislative provision in section 26 a.1 of the Act offers another means of intervention in stipulating that the Office may “make representations on behalf of a handicapped person and, in conjunction with advocacy and service organizations, if applicable, provide assistance if that person’s security is threatened, if the person is exploited in any manner or if the person’s basic needs are not met, and, if necessary, request that the authorities concerned conduct an inquiry.” This provision is of particular interest because it makes it possible for the person to be given support under such circumstances. Then there is the protection afforded by the *Youth Protection Act* when the safety or development of a minor is deemed to be compromised. The *Public Curator Act* and the *Regulation respecting the application of the Public Curator Act*, along with the provisions of the *Civil Code of Québec* regarding protection of adults declared incapable, ensure the protection of these persons, notably by measures adapted to their condition and situation.

5.3 Devise barrier-free laws, policies, programs and services

Action must be undertaken to prevent future barriers to the social participation of handicapped persons when laws, policies, programs and services intended for all citizens are amended. In recent decades, a milestone was reached in developing services for handicapped persons and in establishing policies specifically for them. However, public laws, policies, programs and services are prisms that reflect a society in constant flux. All agencies must consider the conditions that would provide handicapped persons full access to their services, programs and policies at the drawing-board stage. In many cases, it was only further to action by the Office, advocacy groups or other partners that the required catch-up began or that initial omissions were corrected through the introduction of special measures or steps. The needs and characteristics of handicapped persons and of their families must be taken into account systematically when laws, policies, and programs of general scope are drafted.

The means for achieving this are as follows:

a) implementation of and compliance with existing legislative provisions; b) enforcement of the impact clause; and c) awareness and training of staff who draft public legislation, policies and programs.

a) Implementation of and compliance with existing legislative provisions

The 2004 legislative reform unequivocally reaffirmed the primacy of human rights principles and made a formal appeal to the partners to take real measures to make society more inclusive for handicapped persons.⁹ Take, for example, the government policy on access to documents and services (s. 26.5), the obligations stemming from the production of a mandatory annual action plan (s. 61.1), the obligation to provide for handicapped persons' accessibility to goods and services as part of the procurement process (s. 61.3) and public transit development plans (s. 67). As said previously, the Office was given the responsibility of promoting, "in the training programs of university, college and secondary level educational institutions and organizations responsible for vocational training, the inclusion of elements dealing with the adaptation of interventions and services for handicapped persons," and of "promoting the creation of information and training programs designed to foster a better understanding of handicapped persons, their needs and the conditions conducive to their integration into and participation in community life" (s. 25e.1 and 25 g.1). To recap, in the coming years, the Government of Québec must see to efficient implementation of and compliance with existing inclusion-related legislative provisions.

⁹ The government intention here was to have all its partners involved in fostering the integration of handicapped persons to the same extent as other citizens through various measures focusing on their living environment and on developing and organizing resources and services with these persons in mind (s. 1.1). The Act goes on to describe the guidelines for fostering the adaptation of the built environment to the needs of handicapped persons (s. 1.2d).

b) Enforcement of the impact clause

It is paramount that future government policies systematically factor in the specific needs and characteristics of handicapped persons and of their families. Hence, the obligation for government departments and agencies to consult the minister responsible for enforcement of the Act when drafting legislative measures that could have a significant impact on handicapped persons. This "impact clause" makes the authorities from various sectors of activity accountable and is therefore an important lever for an inclusive approach. This is why government department and agency staff assigned to compose and analyze draft bills, as well as those involved in crafting policies or programs, must be better equipped to take the particular situation of handicapped persons into account.

c) Awareness and training of staff who draft public legislation, policies and programs

The people who craft public legislation, policies and programs, as well as those who analyze these instruments, must be more aware of and better trained to understand the social process behind handicapping situations, along with the needs and potential for integration of handicapped persons and of their families. In its capacity as monitor and coordinator, the Office assists its government partners and puts its expertise at their disposal. The advocacy movement also plays a leading role. However, more structured awareness and training activities are needed to better prepare provincial, regional or local staff to perform the task of producing inclusive legislation, policies and programs.

5.4 Take into account the diversity of family structures in drafting family policy

Family policy is an important component of public policy and has a major role to play in improving the situation of the families composed of handicapped persons and the situation of significant others. Like the previous priority, this priority applies specifically to the drafting of family policy.

In recent years, much work has been done by the government to better define and support its action on this front. The difficulties that families and natural caregivers face, especially in blending home life and their obligations in the workplace, have been studied and the measures established in the aftermath of these exercises have been important steps forward, for example, adjustments to the Labour Code. It is worth pointing out that these measures were the result of interdepartmental action and coincided with initiatives to address broader-based issues such as gender equality, social development, and the fight against poverty and social exclusion, all of which required cross-departmental work.

Families composed of handicapped persons account for a portion of the diversity that characterizes Québec families as a whole, notably, members of ethnocultural communities, blended families, adopted families and foster families. Families that have one or more handicapped persons are also highly diverse in composition, e.g. childless couples, families composed of a handicapped spouse or in which both spouses are handicapped, families with handicapped minors or handicapped children of the age of majority, families in which the parents are handicapped and, in many cases, families in which the parents and children are handicapped. The bottom line is that any action taken for and with families must make this diversity a central factor.

Two means are particularly important in implementing this priority: a) bringing the various stakeholders together; and b) supporting innovation given the new face of society and of the family.

a) Bringing the various stakeholders together

The Government of Québec is not the only jurisdiction in matters of family policy. Families are being given an increasingly high profile on the municipal level, which has translated into greater action and, in turn, creation of family policies.

Municipalities must be encouraged to develop an integrated approach in addressing families through coordinated and coherent action in its various sectors of activity. Since municipalities with 15,000 inhabitants or more are legally obliged to produce an annual action plan to reduce barriers to the social integration of handicapped persons within their areas of responsibility, these plans could be designed to include action for families. This is why collaboration with the municipal level must continue.

The expertise of the families of handicapped persons and of their representatives must be put to use in establishing collaborative initiatives and partnerships. Over the years, they have become proficient at knowing the needs of their members and at how to meet them.

b) Support for innovation given the new face of society and of the family

Québec families have undergone tremendous change in recent decades, and families with handicapped members are no exception. This new reality calls for innovation and support thereof. A compelling example of these changes is the increase in the number of parents with intellectual disabilities, due in part to the movement to deinstitutionalize them, to greater integration by them within various social spheres, and to fuller recognition of their rights. Another fact is the greying of the parents of handicapped children. With their and their children's life expectancy vastly improved, these parents worry about their future fitness to care for their children and the longer-term financial security of their adult children. Know-how will also have to be developed in terms of support for single handicapped parents and care for their children as the parents grow older.

Demographic trends combined with the new forms of family life will pose new challenges. As the population ages, more families will be faced with the fact that one of their members or more will have an impairment. Given the shrinking size of families, adult children will have more seniors to care for.

5.5 Design accessible environments

Accessibility to public areas, transportation infrastructure and means of communication is a must in ensuring the social participation of handicapped persons. Accessibility should not be dealt with piecemeal but must be approached as a single construct that requires joint coordinated action at various levels. This means seeing to the overall coherence of any measures aimed at greater accessibility.

The issues surrounding accessibility go far beyond the needs of persons with motor disabilities. Instead, accessibility is meant to improve the situation of every citizen. Accessibility should enable universal access to goods and services, make the built environment user-friendly, and optimize the use of the various means of transportation and communication by one and all, while emphasizing the autonomy of every citizen. In real terms, this entails designing and shaping the built environment on the basis of all users.

In other words, inclusive accessibility must be a core element of every construction or renovation project, at par with safety, to which it obviously contributes. The Supreme Court ruling in the Via Rail case made it clear that cost was not an excuse for maintaining unsafe conditions. It went on to specify that, in the long term, danger is more costly than safety, and discrimination, more costly than inclusion. A number of municipalities have found accessibility solutions that are often simple and affordable. Networks could be created so that municipalities can discuss these experiences. The preferred means for making built environments accessible are to: a) improve physical accessibility; b) improve accessibility to transportation infrastructure; c) improve accessibility to means of communication; and d) take the special characteristics of handicapped persons into account in designing consumer products and in the government procurement process.

a) *Improve physical accessibility*

Inclusivity concentrates on improving conditions for all users rather than relying on instruments specific to certain segments of the population. As a corollary of this is the need to design environments and facilities suitable for all users.

Improved accessibility to public buildings and outdoor facilities is one of the main ways of making these sites available to handicapped persons and of enabling them to move about autonomously and safely, to orient themselves, and to get to their destination. This implies the presence of proper signage and signals. Furthermore, handicapped persons must be able to use the amenities at these locations, such as washrooms, public phones, ATMs, reception desks, drinking fountains, and Internet facilities. Their safety must also be ensured through the use of visual alarm systems, adapted emergency measures, and identification of evacuation methods and of refuge areas.

However, accessible environments are not synonymous with seamless movement from A to B, coherence with other components of the environment, or planning based on the services offered. For example, an accessible library could be located in an area where the transportation system is not adapted or accessible. The point here is that there must be uninterrupted access for handicapped persons so that they can truly use public buildings and built environments. In addition, the services offered within a given environment may not be accessible. Signage, communication systems, auditory signals, lighting and upkeep are other factors that could impede the movement continuum.

b) *Improve accessibility to transportation infrastructure*

Much remains to be done to make it easier for handicapped persons to get to their chosen destination. Despite numerous gains, the fact is that regular means of transportation in Québec do not always provide handicapped persons the same versatility and quality of services as those intended for other passengers. Fairly sizable public investment in adapted transportation has been made at the expense of regular transportation system accessibility. In the absence of technology that would make the regular system accessible, the various levels of government and transportation authorities have created parallel systems, resulting in lack of coordination among the various components of the adapted and specialized transportation systems funded by the Ministère des Transports du

Québec, (MTQ), the Ministère de l'Éducation, du Loisir et du Sport (MELS) and the Ministère de la Santé et des Services sociaux (MSSS), and in patchy scheduling and coverage. Today these are major barriers that prevent handicapped persons from easily getting to where they want to go.

Québec's mass transit policy highlights the importance of accessibility, not only through its general aims and objectives, but also through the specific commitments made to it. Precisely because transportation is a must, it is crucial that significant progress be made not only in terms of accessibility to the various modes of transportation (go-trains, buses, subways) and of optimizing adapted transportation services, but also as regards intermodal accessibility and the long-term operability of new equipment. Interconnectivity between adapted and specialized networks and regular networks must also be achieved with a view to seamless movement throughout and across the system. This approach also opens the way for improved public transit as a whole. Certain rural community projects are especially promising.

Naturally, all related infrastructure must be in good repair, notably in winter, and Québec transportation system employees must be better trained.

c) Improve accessibility to means of communication

In recent decades, Québec society has undergone sweeping changes due to advances in communications. Whether the World Wide Web, cell phones or new televisual technology, means of communication have reached an unprecedented level of sophistication.

Given its wide swath, the field of communications is front and centre when it comes to an accessible environment. This is not without its challenges, including that of making it easier for handicapped persons to use them. One of the first things that must be done is to develop accessibility to the Web sites and e-documents produced

by government departments and public, private and community agencies.

In December 2006, in compliance with section 26.5 of the Act, the Government of Québec adopted a policy to provide handicapped persons with access to public documents and services. Under this policy, the instances concerned are directed to provide reasonable accommodation enabling handicapped persons to have access to the documents and services available to the public. The policy, which also insists on the importance of proactivity in this regard, is part and parcel of an inclusive approach by which all users, including those with impairments, have access to means of communication so that handicapping situations are prevented. The Government of Québec is currently seeking innovative ways of improving the accessibility and quality of its means of communication. One of the particularly important projects underway involves establishing government standards for the Internet access of handicapped persons.

Another way of enhancing accessibility is by promoting the development of barrier-free information and communications technology (ICT). The private sector is a strong presence in telecommunications and in print media and is therefore a prime player not only in developing technology products, but also in terms of telecommunication services and audiovisual production. The Canadian Radio-television and Telecommunications Commission (CRTC) has intervened in several instances to have telecommunications firms do more to adapt their phone services and audiovisual production to the needs of handicapped persons. For example, one of their rulings made it mandatory for broadcasters to subtitle 100% of their programs as of September 2008.

In a world in which ICT is evolving at lightning speed and the private sector is a prized partner, there is a pressing need for mechanisms that enable exchange between the private companies concerned, the Government of Québec, and the groups that represent handicapped persons. Such mechanisms would foster greater awareness of the needs of handicapped

persons by the private sector at the blueprint stage of designing new means of communication. A firmer grasp of these needs could also have an impact on fees charged for certain services, which could put an end to additional impairment-related expenses incurred by handicapped persons in using ICT.

d) Take the needs of handicapped persons into account in designing consumer products and in government procurement practices

Consumer products designed with handicapped persons in mind can improve product safety and quality for the public as a whole. Despite the advantages thus afforded for the self-sufficiency and social participation of handicapped persons, the issue of the accessibility of consumer products, such as household appliances, office equipment, and user-friendly recreational products, is sparsely documented. Consequently, one of the first courses of action for gains on this front is research on the ways of fostering the creation of consumer products that are functional and user-friendly for all.

A second course of action is to improve the accessibility of goods purchased or leased by government departments, municipalities, and public, private and community agencies as part of their procurement process. This is in keeping with section 61.3 of the Act, which states that “when purchasing or leasing goods and services, as part of their procurement process, government departments, public agencies and municipalities must consider whether or not the goods and services are accessible to handicapped persons.” For example, accessible office equipment and furniture, such as desks, photocopier machines, phones, telecommunications equipment and service counters, can be chosen instead of non-accessible wares. The same applies to recreational facilities and equipment and to parking lots, parking meters or parking ticket machines.

The government could also be proactive with the private sector by contributing to the drafting of quality and safety standards governing the domestic sale of accessible products.



6. A UNIFIED AND MORE EQUITABLE SOCIETY

Acting to meet the challenge of a unified and more equitable society also means investing in developing Québec. To do this, there are three courses of action that the partners must embark on together, namely, act against the poverty of handicapped persons and of their families; aim for adequate compensation for additional costs associated with impairments, disabilities and handicapping situations; and increase access to, complementarity and coordination of programs and services.

6.1 Act against the poverty of handicapped persons and of their families

It bears repeating that handicapped persons and their families are frequent victims of poverty. Their personal income is below average and they are more likely to live below the low-income threshold, especially in the case of women. The figures also show that their situation has worsened in recent years compared with that of other Canadians and that the gap is ever widening. Handicapped persons and their families continue to grapple with real barriers to their financial security. Poverty impinges on every aspect of their lives and seriously compromises their social participation. Clearly, if handicapped persons and their families are to have equal access as other citizens to environments that foster their health, happiness and social engagement, a battle must be waged against the poverty that afflicts them. Work as a means of integration must also be promoted, along with openness to the potential of handicapped persons. This investment in human resources is paramount. Given prevailing workforce shortages, Québec cannot afford to disregard this human capital.

Three courses of action have been identified for acting to eradicate the poverty of individuals and of their families: a) concerted action against poverty and social exclusion; b) greater income support; and

c) fewer disparities in terms of income support. These means are bolstered by other actions to compensate handicapped persons for the extra costs they incur because of their disabilities, impairments and handicapping situations, as discussed in the priority that follows this one.

a) *Concerted action against poverty and social exclusion*

The fight against poverty and social exclusion is a leading issue within Québec public policy. Concerted action to improve the living conditions of handicapped persons is even more crucial given the special difficulties so many of them face. This is why measures for social housing, including adapted apartments, a hike in the minimum wage, and other measures to assist individuals and families can have a positive impact on the socioeconomic conditions of handicapped persons. Under the *Act to combat poverty and social exclusion*, the specific needs of certain groups, including handicapped persons, must be taken into account, especially in terms of action to help them enter the workforce and of recognition of the value of work.

To sum up, the idea here is to work on general issues that concern Quebecers as a whole, in collaboration with the various public and community players involved in combating poverty and social exclusion. The policy is an integral part of the response to this social challenge

b) *Greater income support*

Greater income support is the second goal. It can be achieved by increasing the basic income of handicapped persons and of their families. In Québec, the level of income support to handicapped adults who have never worked or have worked very little and therefore have not paid into the State pension plan is low.

Furthermore, certain measures and legislative provisions pertaining to taxation or other matters

use family income in establishing financial assistance amounts. The simple fact of having a family that provides support may reduce the probability of obtaining assistance. This way of doing things does nothing to acknowledge the financial self-reliance of handicapped persons and does not consider the special role played by families and significant others. The problem is compounded for handicapped persons who must deal with heavy additional costs, more particularly, couples or aspiring couples.

This means doing something about the level of financial support for handicapped persons who are not part of the labour force, with a view to improving their financial independence and making it possible for them to form lasting relationships. This is not to be construed with granting privileges that disregard the rules that apply to all citizens. What is required instead is to establish processes that take into account the special circumstances of handicapped persons and of their relationships with others.

Another way of achieving this goal is to improve the net income of low-income handicapped workers or handicapped persons who are making their way towards employment. Current mechanisms contain certain features that provide fewer incentives for them to join the workforce and that could conceivably be deterrents to employment or job retention. As it now stands, Social Solidarity Program participants with a severely limited capacity for employment, who account for a high proportion of handicapped persons, see their benefits cut or reduced if they have earnings or if they go back to school which, understandably, affects their motivation to escape the clutches of poverty. Furthermore, the net gain from earnings can be negligible or non-existent, part of the reason being a shortage of work hours. New measures are needed or existing ones need to be adjusted to take the special needs of workers or prospective handicapped workers into account.

Since 2005, there has been a work premium in the form of a refundable tax credit for Québec's low- or average-income workers. The purpose of this

measure is to make employment an option that pays off and to encourage social assistance recipients to enter the workforce. In 2007, the federal government introduced a working income tax benefit which, like Québec mechanisms, is designed to make work a profitable proposition by increasing workers' net income. The benefit also includes a specific supplement for handicapped persons. These means are examples of the kinds of permanent and targeted actions that can be built upon, in combination with other worthwhile initiatives that must be supported and continued.

c) Fewer disparities in terms of income support

Action must also be taken to reduce disparities in income support. Currently there are sizable variations in income coverage for certain categories of handicapped adults. For example, there are significant differences in the level of income support or income replacement among victims of acts of crime or of good citizenship, in the level of compensation arising from use of a Héma-Québec product or an immunization program, in the monies paid out to persons infected with hepatitis C, to Social Solidarity Program participants with a severely limited capacity for employment, and to disability pension claimants. These disparities exist despite the fact that all of them, except for the Régie des rentes du Québec's disability pension, are financed under the Consolidated Revenue Fund.

Granted, this is not an easy issue, but it is one that many handicapped persons have long wanted to broach. Realistic and socially acceptable solutions will have to be found to reduce the disparities in the income support provided under plans and compensation measures funded from this same source.

6.2 Aim for adequate compensation for additional costs associated with impairments, disabilities and handicapping situations

Despite a number of improvements in recent years, the response to the needs of handicapped persons and of their families remains a cause for concern. The response to these needs can be

monetary, for example, allowances, tax deductions or credits, or by means of reimbursement of additional expenses in the form of special benefits under last-resort financial assistance programs, or through the provision of services and equipment. These responses are interconnected and have an incidence on each other. The upshot is that handicapped persons and their families may find themselves in very different situations in this regard, some receiving direct services such as rehabilitation or homecare, while others must foot the bill themselves or must rely on family members to provide them with personal assistance or to escort them for certain activities. In some cases, they must pay out of pocket for services from private or community businesses and be reimbursed subsequently if at all. Service access problems have a major impact on the fees that handicapped persons and their families must cover.

This is why a comprehensive approach must be used in responding to the needs of handicapped persons and of their families. This priority applies in particular to additional out-of-pocket expenses and the benefits received to deal with these expenses. The issue of services and equipment is addressed in the next priority that concerns better access to, complementarity and coordination of programs and services.

Many handicapped persons and their families must assume the fees stemming from their deficiencies, impairments and handicapping situations. This, of course, increases the risk of poverty. The bigger the share of uncovered costs in relation to the family budget, the more likely handicapped persons and their families are to slip into poverty, at times to the point of destitution. These extra costs can also jeopardize their social participation.

Basically, handicapped persons and their families have extra costs that are not standard and that chip away at their disposable income. If these extra costs are not recognized or if no special measures are available, proportionally, their financial obligations far exceed those of other families and individuals.

For example, without support, their tax burden is the same as that of families that do not have these additional budget items. The budget and tax support programs established by governments is their way of restoring balance.

A portion of these additional costs is almost impossible to pin down specifically. Some of them stem from the fact that handicapped persons and their families spend more on everyday goods and services than the average for other families. These costs are difficult to assign to a particular debit column because they are vague and involve multiple transactions. Here we are referring, for example, to their need to live near services, where housing costs are higher, or the higher insurance premiums they are required to pay. Despite the gamut of measures for which handicapped persons and their families are eligible, there are always extra costs because needs are highly diverse.

These outlays, under the heading of general additional costs, are usually compensated through tax measures specifically for handicapped persons or their families, or by specific benefits. Québec and Canada have two basic tax credits designed to make their respective personal income tax systems fairer for handicapped persons. The United States and France are among the countries that have measures similar to those of Québec and Canada. Other countries, such as the United Kingdom, have a non-taxable benefit issued directly to recipients. This type of measure is what is used in Québec and Canada for handicapped children.

Another portion of the additional expenses of handicapped persons and of their families is for specific costs that are easier to identify, namely, those related to medical care, medication, rehabilitation, technical aids, home assistance, respite services, and so forth. The most common form of compensation for these costs is through the provision of services and equipment, and in some cases by monetary transfers by means of budget or tax instruments. Currently, Québec has a mixed formula. For example, a wheelchair can be provided

under a technical aids program or bought directly then used as a tax credit for medical expenses.

There must be greater equity between handicapped persons and other members of society as well as between the families of handicapped persons and other families. Four means are available for achieving this goal: a) full compensation of general additional costs; b) non-income based compensation of general additional costs; c) improved tax measures that more directly concern handicapped persons, their families and significant others; and d) an improved public prescribed drug insurance plan.

a) Full compensation of general additional costs

Québec partly recognizes the general additional costs that handicapped persons and their families must carry. However, existing financial compensation instruments apply only to a narrow segment of this population. Furthermore, there is no clear evidence that the compensation granted is minimally equivalent to the real cost average.

Partial recognition of general additional costs, like insufficient income support, is a determinative factor in the erosion of the living conditions of handicapped persons and of other members of their family. Efforts must be made to provide more adequate coverage of these costs. Corrective measures could be introduced progressively.

b) Non-income based compensation of general additional costs

In recent years, the principle of non-income based compensation of general additional costs has been used for all handicapped children in Québec. There are two direct and virtually universal tax-free benefits, one from the provincial government (Supplement for Handicapped Children), and one from the federal government (Child Disability Benefit). This financial assistance is not always sufficient, but the benefits are relatively simple for parents to understand and for agencies to administer. The benefits are issued on a monthly

or quarterly basis and are indexed annually. The instruments used for other handicapped persons are modeled on this type of measure.

There are two tax credits for adults, one, provincial, and the other, federal. Again, only a portion of the adult handicapped population is entitled because the credits apply only to tax payers. This means that people whose income is so low that they do not pay taxes do not have access to the credits. Tax payers who would be eligible for the credits are sometimes unaware of them. The current system must be made more equitable by giving all handicapped adults in Québec, including those with low incomes, the same access to compensation of general additional costs.

c) Improved tax measures that more directly concern handicapped persons, their families and significant others

Compensation in the form of monetary benefits is a good way of covering general additional costs, medication and travel expenses, whereas compensation in the form of services or equipment is the preferred means for meeting the majority of specific needs.

Tax measures are another government mechanism that give individuals and businesses a boost in achieving certain strategic objectives on the economic, social, cultural and other fronts. The vast array of tax measures makes this mechanism highly flexible, applicable to a wide range of areas, and generative of a great variety of economic and fiscal effects. Tax measures can be used in lieu of direct financial assistance.

There are a relatively high number of Québec tax measures for handicapped persons, designed to provide financial support for and to recognize the needs specific to handicapped persons and their families. These include:

- A tax credit for persons with severe and long-term physical or mental impairments;

- The Supplement for Handicapped Children under the refundable tax credit for child assistance;
- The Work Premium for persons with a severely limited capacity for employment;
- Refundable and non-refundable tax credits for medical expenses.

Payments are generally made only once a year and a number of credits are not refundable unless the applicant pays taxes. Many handicapped persons do not pay taxes because their income is too low, and in those cases, certain measures do not provide support. Other measures require allowable expenses that account for a hefty proportion of the person's or the family's income. Furthermore, allowable expenses do not always cover the goods, equipment or services, whether specialized or not, required by handicapped persons.

Despite the many tax improvements in recent years, there are a number of remaining avenues that would make it possible to increase the financial support afforded by tax measures for handicapped persons, their families, and their network of support, notably in terms of medical fees, products and services for supporting handicapped persons, and support for natural caregivers. It bears pointing out that the amounts earmarked for tax measures have become considerable, and that these amounts must be divided up more fairly so that the most underprivileged handicapped persons can benefit.

d) An improved public prescription drug insurance plan

Since its creation in 1997, Québec's prescription drug insurance plan has made medication free for the children, including, under certain conditions, students aged 18 to 25, of publicly insured adults. In certain cases, the system also provides prescription drugs free of charge to independent adults with severe chronic mental or physical impairments that began before age 18 and who are not last-resort financial assistance recipients. Recently a number of improvements

have been made to the system.¹⁰ In addition to the above, the system also provides full coverage for last-resort financial assistance recipients with or without a severely limited capacity for employment, as well as for Guaranteed Income Supplement recipients whose benefits represent at least 94% of the Supplement maximum. Other publicly and privately insured claimants pay a capped amount upon purchase of prescribed medication. The public plan also provides for an income-adjusted annual premium. All of these provisions increase access to prescription drugs, especially for handicapped persons. These measures that benefit all citizens must be maintained.

6.3 Increase access to, complementarity and coordination of programs and services

Handicapped persons and their families experience a range of difficulties in gaining equitable access to programs, services and equipment that meet their needs. Complementarity and coordination of these programs and services could be bettered, more specifically: a) improved general access to plans, programs and services; b) improved access to and adaptation of existing services; and c) improved complementarity and coordination of programs and services

a) Improved general access to plans, programs and services

More than 200 public measures that can assist handicapped persons and their families either directly or indirectly are in effect in Québec. Established by the Government of Québec and the federal government and managed by various government departments and agencies, these programs act on the level of income or taxes and undergo frequent

¹⁰ In July 2005, complete coverage of medication was extended to include seniors who receive the maximum amount under the Guaranteed Income Supplement (GIS). In July 2007, it was again extended to include employment-assistance recipients without severe limitations and to seniors who receive GIS benefits equivalent to at least 94% of the maximum amount.

change. Together, they form a complex and mutable maze that even specialists find difficult to navigate. The logistics of accessing them can be lengthy, frustrating and fruitless.

Therefore, one of the first ways of securing better access to services is to simplify and improve access to information. This is the primary prerequisite for better access and equity and the first thing that must be done so that handicapped persons and their families have more control over their lives and exercise real choices in terms of their needs. The challenge is to create a genuine “one-stop outlet” that provides general information about available services. A number of such initiatives, all of which have shown that there is a crying need for a clearinghouse for information, have already been undertaken, namely by Services Québec, Revenu Québec, the Public Curator and the Office. The next step is to bring them together or coordinate them in order to boost the benefits thereof. The gateway to this information must be known, user-friendly and accessible to all via various means of communication.

The second course of action is to harmonize eligibility criteria and streamline evaluation. There is a flagrant lack of harmonization of the eligibility requirements for the different programs and services, which each have their own conditions based on medical, administrative, legal and other considerations and on precedent. Handicapped persons and their families must undergo evaluation that is often heavy and repetitive. They must constantly provide proof of their needs, complete and submit forms, have medical examinations, and, in some cases, begin the entire process over again the year after. While specific tests are necessary, much can be done to enhance the harmonization of eligibility criteria and streamline needs evaluation. Promotion of the use of a standardized classification system for impairments, disabilities and handicapping situations, as well as joint action with a view to standardizing rules and simplifying procedures, are the main options envisaged.

Establishing means of guaranteeing the response to basic needs with regard to the integrity and safety

of handicapped persons is part of the above process. Currently, there are wait times and waiting lists for evaluations, treatment and services. The problem lies mainly in the potential for ill effects arising from delays in areas that concern the basic needs of handicapped persons or of their network of support.

Implementation of ways of guaranteeing the response to these fundamental needs necessarily involves identifying the array of basic services to be provided according to broad categories of clients, or, practically speaking, on the basis of the impairment or disability. The problem of wait times and waiting lists is a tough one to solve, and a reliable cost estimate is difficult to produce. Obviously, hefty financial investments and substantial administrative changes will have to be made to reduce wait times and waiting lists. Given the prevailing financial context, organizational constraints and the shortage of specialized resources such as physicians, occupational therapists, and speech therapists, it will be hard to rectify the full spectrum of problems in the short term. However, targeted action aimed at priority issues could improve the situation significantly.

The reduction of disparities stemming from cause, age or living environment must also be addressed if service access is to improve. These disparities adversely affect the quality of the responses to needs and raise sensitive questions of equity. They show the critical role played by factors such as when and where impairments or disabilities first occur in determining which services will be provided to handicapped persons who, despite the universal social safety net, can fall through the cracks when the system fails. Congenital impairments or impairments arising from illness or accidents that are not occupational or highway-related are the most troubling causes in terms of equity because they account for most handicapped persons. Medical errors and certain types of infection as causes have also been of increasing concern in recent years.

While it is clear that plans funded by individual groups of citizens, such as the insurance plans managed by the Commission de la santé et de la sécurité du travail

and the Société de l'assurance automobile du Québec, must be kept separate from the indemnity plans under the Consolidated Revenue Fund, they must be properly integrated within the entire compensation system in operation in Québec. The beneficiaries of the plans in question must be granted similar compensation in similar situations, even if the State has a strong say in determining the amount of compensation allowed. Furthermore, the government must remain alert and intervene as needed when the public liability system does not compensate the victims of other forms of personal injury under reasonable conditions and within a reasonable timeframe. This search for equity calls for concerted action and solidarity by all citizens.

The consequences of inadequate access to resources for handicapped persons, their families and significant others are severe and seriously hamper their social participation. More and more experts are also saying that the toll on the economy is heavy indeed. The more ineffective the access system is, the more it spawns poverty, social and new health problems whose costs are increasingly difficult for society to absorb. Quicker and fairer access to the response to needs leads to better overall social and economic performance by a society.

b) Improved access to and adaptation of current services

As discussed previously in outlining the features of an inclusive society, handicapped persons must be able to use everyday services rather than constantly being referred to specialized services to meet needs that are unrelated to their impairments or disabilities. Take, for example, dental care, hairdressing or seeing a notary. The more inclusive the society, the less the reliance of handicapped persons on special adaptations or services will be. Note, however, that even within a successfully inclusive society, a certain amount of adaptation will always be required simply because of the diversity of handicapped persons.

The barriers that handicapped persons face can be physical, technological, or communicational, or may be related to the attitudes or ignorance of the people

who dispense services. Efforts must be made to induce service providers to adjust to the situations experienced by handicapped persons, especially given that there will be more and more handicapped persons in the future because of our aging population.

c) Strengthening the fit between and the coordination of programs and services

The impressive program and service infrastructure in response to the needs of handicapped persons and of their families has been a major gain in the past few decades that must be maintained and developed in order to improve access and equity. However, because there are so many programs and instances involved in planning and providing these services, there must be greater emphasis on strengthening their fit and coordination through inter-sectoral action.

The agreements entered into by broad-based service networks, such as those between MSSS and MELS, are interesting examples of ways of improving service complementarity and coordination. Other more modest initiatives should also be developed.

Collaboration among the different service networks at crucial transitional stages in the lives of handicapped individuals is another course of action that must be pursued. For example, the integration of handicapped children within childcare may require collaboration with other service networks. This collaboration is not a given, due to the shortage of adaptation-rehabilitation resources. The transition from school to the job market is another important phase for which many handicapped persons need structured support that involves a number of networks, such as education, adaptation-rehabilitation, and labour. The efforts made thus far on this front must continue.

Establishing Québec-wide guidelines for action is another way of achieving the goal of providing sufficient quantities of quality services. For this to happen, the regional application of these guidelines must take into account the intervention sector concerned, the nature of the programs, the

context in which they will operate, including the existing legislative framework, and the constraints specific to each region. Another promising means of supporting inter-sectoral action at the regional and local level is through common coordination instruments. Any regional or local initiatives that prove successful should be examined in order to craft flexible models that can be used across Québec.

Another worthwhile avenue is the potential contribution of the municipal community in supporting inter-sectoral initiatives that have produced positive results, as a number of municipalities have already done. These success stories must be documented more extensively and assessed for their suitability for more widespread use.

The voluntary and effective participation of local advocacy groups of handicapped persons and their families in local inter-sectoral joint action is to be encouraged. However, resources are required to cover supplementary costs arising from the participation of handicapped persons. Appropriate resources would make it possible to benefit fully from the expertise and unique contribution of these groups within the framework of their overall mission.

7. A SOCIETY THAT RESPECTS THE CHOICES AND NEEDS OF HANDICAPPED PERSONS AND OF THEIR FAMILIES

To meet this challenge, three priority thrusts are proposed: make individualized and coordinated service planning standard practice; support the exercise of family and social roles by the families of handicapped persons; and make structured accompaniment services accessible to handicapped persons and their families.

7.1 Make individualized and coordinated service planning standard practice

As part of the process of social integration, handicapped persons must interact with a variety of players if their full array of needs is to be met. The approach used should therefore be one that respects their individuality and their every dimension, in other words, one that makes individualized and coordinated service planning possible. The idea is to achieve seamless service provision and coherent and coordinated action by the different players in order to respond to needs, based on the specificities of the individual so that the person can achieve his or her objectives. While, by definition, individualized and coordinated service planning is an approach that focuses on the individual, it must also take into account the needs of the person's family and all the factors that influence the social participation of handicapped persons, whether environmental or personal.

Individualized and coordinated service planning can be broken down into three areas of action: a personalized and satisfactory response to the needs of the person; more control by the person of the services required to foster his or her social integration; and service coherence, complementarity and continuity by coordinating action by the partners from the different public, parapublic and

private networks. It bears repeating that the basic tenets of the Act advocating the independence and free choice of the person suppose that the person's wishes must prevail over organizational or administrative concerns.

In turn, respect of the person's independence implies a comprehensive assessment of his or her abilities, skills and needs, along with the person's personal goals and of the means required for achievement of these objectives. By being active participants in service planning, clients can have a say in the services offered to them.

Tailoring the slate of services to the individual's needs and specificities also means establishing practices centred on problem-solving. All players concerned work together to identify needs, find appropriate, creative and innovative solutions for meeting needs, and fine-tune the response as required.

Making individualized and coordinated service planning standard practice requires the following conditions: a) use of the service program by all players; b) a harmonized vision of the service program and of the terminology used; c) confidentiality by all players; d) a mixed model for service program coordination; e) rules governing consent in designating a service program coordinator; and f) recognition of the contribution of families and significant others in the process of service planning and coordination.

a) *Service program use by all players*

The service program is the instrument by which individualized and coordinated service planning is put into action. Service programs make it possible to identify, formalize, and conduct ongoing monitoring

of the needs of handicapped persons, the services to be dispensed, the services dispensed, unmet needs, steps to be taken, commitments made by institutions or agencies, and so forth.

Note that despite the legal obligations and the ministerial policies in effect, practices with regard to service programs vary widely according to the nature of the impairment and, sometimes, even according to its cause. Service programs are used more extensively with intellectual disability clients. In the field of physical disabilities, their use varies depending on the institution, and in the mental health sector, there is marked resistance to their use. Certain service program practices (individual rehabilitation plans in the case of the Commission de la santé et de la sécurité du travail; and social, educational and occupational re-entry plans in the case of the Société de l'assurance automobile du Québec) are standard and systematic components of the courses of action used in Québec's public insurance regimes.

Concerted efforts by all the players concerned are therefore necessary so that effective practices are consistent with the legal obligations and ministerial policies, aims and objectives that govern services to handicapped persons, an exercise that yields better results when carried out upstream of crisis situations. It is especially useful in helping clients transition smoothly from one phase of life to the next.

b) A harmonized vision of the service program and of the terminology used

There are two basic visions of what service program practices should be, and these two paradigms do not necessarily mesh. This, of course, makes the harmonization of practices even more daunting. Under one paradigm, service programs are seen as a cluster of action plans from a specific institution, resulting in services limited to its fields of expertise. This view of the service program assumes that client needs will be taken care of within the framework of a predetermined slate of services that must be coordinated. However, service programs as described in the *On Equal Terms* policy are based instead on

broad areas of intervention, for example, employment, educational services, and rehabilitation, calling for the involvement of various institutions in response to a specific need. This radically different approach is geared first and foremost to identifying a person's needs. For each field of intervention, the response to a specific need could require the contribution of various partners who, in turn, would adjust, adapt or develop their services accordingly. Here, what is coordinated is not a specific suite of services but a response tailored to needs. Service program practices must be re-thought based on the latter vision.

Every sector of activity, e.g. health and social services, education, youth, has its own definition of a service program and uses its own terminology. A number of studies on the subject come to the same conclusion regarding this divergence and therefore suggest the adoption of two terms, namely, individualized service programs and inter-sectoral individualized service programs. Harmonization initiatives must continue so that all the players concerned can agree on a common vision and common terminology that will prevent ambiguity.

c) Confidentiality by all players

Since information must be exchanged between various players within the networks involved in producing service programs as part of the process of individualized and coordinated planning, the question of confidentiality and protection of personal information is significant. Free and informed consent for the transmission of personal information in accordance with the relevant legislation is the rule of thumb. One of the ways of ensuring confidentiality is by creating a consent form along with an explanatory guide and distributing it to the people who work with handicapped persons, these clients and their families.

d) A mixed model for service program coordination

To achieve coherent and complementary action by the different players, coordination mechanisms must be established. The mechanism suggested in the *On Equal Terms* policy is joint coordination, in which all

parties, especially the handicapped person, and, where applicable, the person's family or significant others, work together to identify needs, services and respective responsibilities. This is not an easy task, which is perhaps why service programs are under-used.

Case management is also another coordination model used by various communities. The service coordinator oversees a comprehensive assessment of the client's situation, needs, expectations and plans for the future. The coordinator also identifies the services required and the partners who will be recruited so that an adapted response to all these needs is achieved. Coordination tasks can also be shared with the client or by more than one case worker.

In order to make coordination less cumbersome, a mixed coordination format may be the answer. In simpler situations, and with the individual's consent, the service coordinator could, through referral, phone contact or discussion with the service provider, ensure that a response to the identified need is found (case management). In more complex situations, joint coordination may be necessary, and a meeting or meetings with all the players concerned, including the handicapped person, and, if necessary, a parent or an attendant of the person's choosing, may prove essential.

e) Rules of consent for designating a service program coordinator

As said previously, handicapped persons can coordinate their service programs themselves with the assistance of a support person if so requested. However, this rarely occurs. Within the framework of service agreements between health and social services and education, the service program coordinator is designated by the various players when the service program is drafted. The person chosen to be the service program coordinator is often the main case worker or the person who, in his or her official capacity, will be assigned the bulk of the work. In the health and social services network, the Navigator often becomes the service program coordinator. Some authors favour the designation of a coordinator specifically trained for that purpose. While it is important that the service program coordinator have

the required skills, the client, who may want to take on the task of fully or partly coordinating the service program, has the final word and is entitled to receive any assistance he or she may need in that respect. The service program coordinator notwithstanding, handicapped persons, parents or significant others must be in agreement with the decisions made.

With a view to harmonizing and standardizing individualized and coordinated service planning, rules must be established for the consent required in designating the person who will be in charge of service program coordination.

f) Recognition of the contribution of families and other natural caregivers to the planning and coordination of services

Families and other natural caregivers play a crucial role with handicapped persons who are minors, who need support in decision-making, or who want someone with them during the process of service planning and coordination. Their opinion must be sought and taken into consideration in evaluating the needs of the person and in the subsequent planning, bearing in mind that the rights of the handicapped person are paramount should any disagreements arise. The family's skills must be acknowledged. In the case of family services, the same approach, based on problem-solving, primacy of the life goals of the family and of significant others, and respect for family expectations, must prevail.

7.2 Support the exercise of family and social roles by the families of handicapped persons

At some point in the lives of handicapped persons, families and loved ones will be called upon to play a leading role in fulfilling their daily needs and for their educational, occupational and social development. Families and loved ones account for most of the assistance given to handicapped persons, and the support they provide is highly diverse, e.g. psychological or emotional support, financial assistance, support in obtaining official services, personal assistance and homecare, and childcare.

This support, albeit essential, is not inexhaustible. The extent of the needs of families and loved ones in their capacity as caregivers must be acknowledged so that they can continue to develop, exercise their roles within the family and within society at large, and successfully juggle their family, occupational and social responsibilities.

These needs are better documented than they were 20 years ago. Today we can say with certainty that these needs are diverse. For example, families with a handicapped minor dependant need assistance with housework and need personal and family time. In families with a handicapped parent, childcare is what is needed. We also know that many families must foot the bill for these needs and that prohibitive cost is one of the main reasons why their needs remain unmet. These families are more likely to be poor and are more subject to broken marriages or relationships, which only adds to the burden they carry. Two courses of action are therefore proposed: a) improved support for families; and b) innovation with a view to gender equality.

a) Improve the support offered to families

The parents of handicapped children should be able to assume that they will have sufficient resources to enable them to fulfil their responsibilities. The same holds true for the significant others who live with or are directly involved with handicapped persons.

Providing better support services for handicapped persons within their living environment is the primary means of supporting families and significant others who do more than their share in terms of assistance. In addition to inclusivity initiatives, family-focused action, whether provincial or municipal, must contain family-specific measures that are comprehensive enough to enable families to exercise their family, professional and social responsibilities as other families do. Note that support needs are particularly glaring in families with members who have severe disabilities. These families have more trouble accessing certain childcare services, especially home daycare, respite facilities, and recreational facilities. All too often, these families are the

sole and full-time providers of assistance. Government and community resources must be marshalled to offer support to these families who need it most.

b) Innovation with a view to gender equality

The repercussions of insufficient support are not the same for men and women because, in most cases, their contribution as caregivers is not the same. Female caregivers far outnumber male caregivers and are more likely to be the main caregiver. Since generally, men's and women's needs are different, more information is a must so that appropriate measures can be developed with a view to a fairer division of responsibilities. Research and innovation is the key.

7.3 Make structured accompaniment services accessible to handicapped persons and their families

This priority is aimed at the development of high-quality structured accompaniment services, either regular or occasional, to mitigate impairments and facilitate social participation. Accompaniment varies according to the needs and characteristics of the handicapped person and those of the person's environment and is carried out through a set of activities.

Accompaniment can be either assistive or substitutive. In the former, persons are helped with their everyday activities, through, for example, assistance in communicating, in dressing, or in getting from point A to point B. In the latter, the attendant does what the person with the disability cannot do. Generally, substitutive accompaniment occurs when the person cannot communicate or tend to everyday tasks or when assistive accompaniment is not sufficient to ensure the person's safety. However, substitutive accompaniment is provided only if the person cannot carry out the activity in question even with assistive accompaniment. This means that a person may require assistive accompaniment at certain times and substitutive accompaniment at others. Furthermore, the person must be free to choose the form of accompaniment. Lastly, it must never be forgotten that the ultimate goal is social participation.

Development of accompaniment services should occur on four fronts: a) accompaniment service development in every region; b) harmonization of accompaniment practices; c) recognition of accompaniment needs in the individualized and coordinated planning of services; and d) better training and wages for attendants.

a) Accompaniment service development in every region

Support services are underdeveloped. More often than not, family members or significant others provide the support that handicapped persons need to carry out their everyday activities. Accompaniment services are also provided by advocacy groups and through community programs that match volunteers one-on-one with a handicapped person. The most structured services are available within the school system, even though services and levels are different from one school board to the next. Municipalities may also have specific accompaniment services, such as recreational services. Given this diversity, there is a need for Québec-wide guidelines for all providers, along with recognition of the fact that the support they give is essential for certain handicapped persons.

b) Harmonization of accompaniment practices

Current organization of accompaniment measures and practices varies widely from municipality to municipality. Existing services are under-funded and they are not always fully refunded, leading to hefty additional expenses. One of the ways to enhance access is to reimburse accompaniment fees and to enable handicapped persons to choose their attendant.

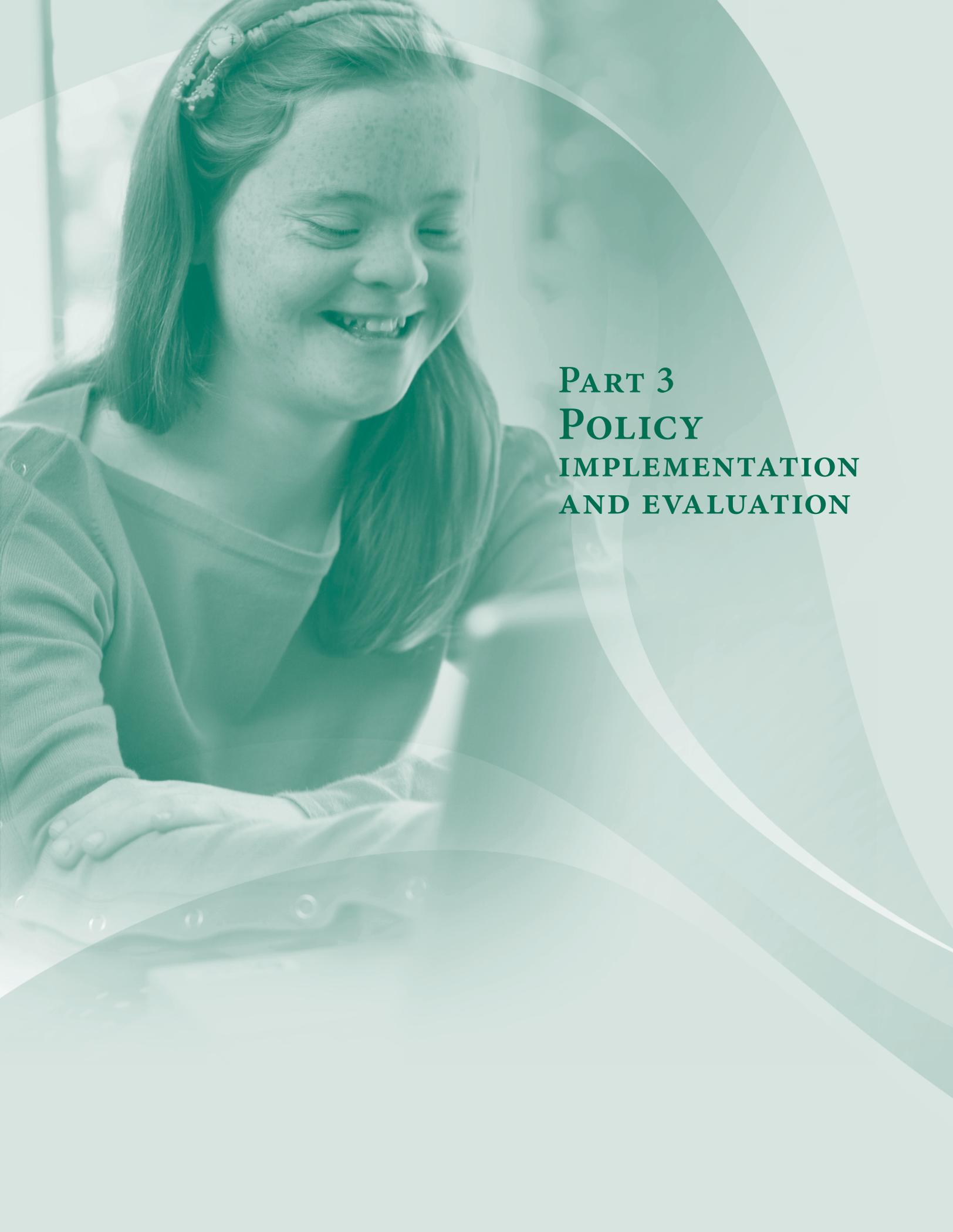
c) Recognition of accompaniment needs in the individualized and coordinated planning of services

All foreseeable accompaniment needs must be built into individualized service programs. The support thus provided would help to reduce the dependence of handicapped persons on their families and on significant others.

d) Better training and wages for attendants

Attendants must have certain basic skills in order to fulfill this role properly. Unfortunately, training either does not exist or is not standardized. Furthermore, there are very few salaried attendants because frequently it is relatives and/or volunteers who provide accompaniment. Often, these volunteers are untrained or scarcely trained, and the trend in recent years has been a decline in the number of people who give of their time. Efforts to structure the services in this sector must take these two crucial factors into account in aiming for quality services.



A young girl with freckles and a headband is smiling and looking down at a book or document. The image is overlaid with a teal circular graphic on the right side.

PART 3
POLICY
IMPLEMENTATION
AND EVALUATION



8. POLICY IMPLEMENTATION

In order to tackle the three main challenges and the eleven thrusts of this policy, special attention must be paid to policy implementation. It bears repeating that the goal is to increase the social participation of handicapped persons in the next ten years.

Strengthening inter-sectoral action

To strengthen inter-sectoral action, cross-departmental action must be stepped up. By definition, this means commitment by all the government department and agencies concerned.

With a view to coherence and efficiency, the policy advocates the use of existing inter-sectoral mechanisms, such as those under the government's action plan to combat poverty and social exclusion and its youth strategy, the health and social services and education agreement, and the National Strategy for Labour Market Integration and Maintenance of Handicapped Persons. All of these will be considered as the preferred means for implementing the policy's priorities and thrusts.

The government has entrusted the Office with the task of spearheading and supporting the inter-sectoral initiatives required for ensuring that all the priorities of the policy are addressed by this cross-sectional action.

Implementing inter-sectoral action to reduce barriers

Achievement of the goal of the policy hinges on inter-sectoral action related to the barriers identified during drafting of the policy.

Implementing section 61.2

Under section 61.2 of the Act, the minister responsible for enforcing the legislation must be consulted during the drafting of measures that could have a significant impact on handicapped persons. There are similar impact clauses in the field of health, for the fight against poverty and social exclusion and for gender equality. With a view to coherent and consistent government action, implementation of section 61.2 will occur within the framework of health impact assessments under the responsibility of MSSS. The Office and MSSS will work together to define the ways of taking the social participation of handicapped persons into account according to their respective areas of jurisdiction.

Means of implementation

The annual action plans prescribed in section 61.1 of the Act, the National Strategy for Labour Market Integration and Maintenance of Handicapped Persons, government departments' and agencies' strategic plans, sector-based policies and action plans, other mandatory plans stemming from the Act, and all public and private initiatives are the preferred means for implementing the policy.

Identification of the means for assuring implementation of the policy by government departments and agencies was coordinated by the Office. These means, collated by the Office to form the first comprehensive implementation plan, will be the basis for the annual action plans required under section 61.1 of the Act or for the policies, strategic plans and action plans for which these government departments and agencies are responsible.

Promotion of the policy

To foster implementation of the policy and action that can impact positively on the social participation of handicapped persons and on the situation of families by all segments of society, including the private and community sector, the government has pledged to promote the policy to all stakeholders and action sectors referred to in the policy.

9. EVALUATION OF THE POLICY

Evaluation of the policy has been entrusted to the Office in keeping with its duty to assess trends in the educational, occupational and social integration of handicapped persons and to make recommendations to the minister responsible for enforcement of the Act. The Office will work with its partners, notably, advocacy groups and handicapped persons and their families, to devise monitoring mechanisms.

Evaluation of the policy should be two-pronged.

Evaluation of implementation

Evaluation of policy implementation will occur by systematically overseeing the means identified by the government departments and agencies. These means concern all of the policy's priorities and thrusts. Monitoring will be carried out using the indicators contained in the department and agency action plans required under section 61.1 of the Act, and in strategic plans, policies and other government initiatives. The Office will use this information to produce guidelines for evaluating how policy implementation is faring.

Evaluation of expected outcomes

The evaluation of social participation outcomes will be conducted using a series of specific indicators for each of the expected results in terms of improvement of the living conditions of handicapped persons and of their social participation. The indicators, broken down by sex, age, impairment type and severity, and region, will be chosen for their relevance and reliability and will make it possible to assess policy effectiveness, in other words, to gauge the progress made with regard to expected outcomes.

In light of the results obtained when follow-up is completed, evaluative research projects using various methodologies will be undertaken so as to better understand why certain expected results, social participation targets or action priorities seem

to be on course, while others are not. In addition to contributing to policy evaluation, evaluative research will provide knowledge about the state of the social participation of handicapped persons in Québec, about the main barriers to participation and, ultimately, about how to better steer the action of the partners involved.

Consequently, this evaluation will shed light on whether or not the goal of the policy has been attained, namely, to increase the social participation of handicapped persons in Québec. The evaluation will also serve to carry out gender-based analysis.

To support policy evaluation, the government:

- Recognizes the policy's expected outcomes as significant changes that Québec should aim for in the next ten years;
- Commits to better documenting the state of the social participation of handicapped persons in Québec;
- Asks the government departments and agencies concerned to table a five-year evaluation report with the Ministère de la Santé et des Services sociaux (Office des personnes handicapées du Québec).



APPENDIX



GLOSSARY

General definitions

Accompaniment:

Accompaniment refers to the services, dispensed on a regular or an occasional basis, to mitigate impairments and facilitate social participation. Accompaniment varies according to the needs and characteristics of the handicapped person and those of the person's environment and is carried out through a set of activities.

Accompaniment can be either **assistive** or substitutive. In assistive accompaniment, persons are helped with their everyday activities, for example, assistance in communicating, in dressing, or in getting from point A to point B. In **substitutive** accompaniment, the attendant does what the handicapped person cannot do.

Act:

Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration (R.S.Q., c. E-20.1). The former 1978 Act whose title was amended in December 2004 by the *Act to amend the Act to secure handicapped persons in the exercise of their rights and other legislative provisions*

1978 Act:

Act to secure handicapped persons in the exercise of their rights (S.Q., 2004, c. 31) assented to unanimously by the National Assembly in June 1978

Compensation:

In common and legal language, compensation is the repair of injury, the righting of a wrong, or correction of a disadvantage imposed by a person or an external event.

In keeping with the revised concept of social participation advocated in this policy, compensation is part of the overall process of neutralizing the inconveniences encountered by handicapped persons within society due to impairments stemming from various causes, so as to enable them to eliminate handicapping situations in their life habits.

In practice, compensation generally covers two areas: income replacement, measured in terms of the loss of a potential gain caused by full or partial inability to hold down a job; and coverage of special needs, which applies to the extra costs stemming from impairments, disabilities or handicapping situations.

Discrimination:

Situation in which full and equal recognition of individual rights and freedoms or the exercise of thereof is denied or compromised by a distinction, exclusion or preference based on race, colour, sex, pregnancy, sexual orientation, civil status, age except as provided by law, religion, political convictions, language, ethnic or national origin, social condition, a handicap or the use of any means to palliate a handicap

Empowerment:

The enhanced ability of individuals or members of a community to have control of their lives and their environment at par with their fellow citizens through awareness, development of their abilities, and action

Exclusion:

Situation in which persons or groups thereof cannot participate in or access one or more spheres of activity (economic, social, political, legal, religious, cultural, etc.) within their society

Person:

“Every human being possesses juridical personality and has the full enjoyment of civil rights.” The recognition of legal personality for all human beings implies that all persons are equal and that “every person is the holder of personality rights, such as the right to life, the right to the inviolability and integrity of his person, and the right to the respect of his name, reputation and privacy.”

Handicapped person:

A person with a deficiency causing a significant and persistent disability (impairment), who is liable to encounter barriers in performing everyday activities.

Definitions related to the Disability Creation Process

A **risk factor** is an element related to the individual or the environment that is likely to give rise to a disease or an injury or any other disruption of a person’s integrity or development.

A **personal factor** refers to a person’s intrinsic characteristics, such as, age, gender, socio-cultural characteristics, organic systems and capabilities.

An **organic system** is defined as a group of biological components sharing a common function.

Integrity corresponds to the quality of an unaltered organic system.

Impairment corresponds to the extent of the anatomical, histological or physiological disruption of an organic system.

A **capability** is defined as a person’s potential to accomplish a mental or physical activity.

Ability corresponds to the positive expression of a capability.

Disability corresponds to the extent of the reduction of a capability.

An **environmental factor** is defined as a physical or social dimension that determines a society’s organization and context.

A **facilitator** is as environmental factor that helps the performance of life habits in interaction with personal factors (deficiencies, disabilities and other characteristics of the person).

An **obstacle** (the more common term and the one used in this policy is “barrier”) is an environmental factor that hinders the performance of life habits in interaction with personal factors (impairments, disabilities and other characteristics of the person).

A **life habit** is a daily activity or social role valued by the person and/or the person’s socio-cultural context based on that person’s characteristics (age, gender, socio-cultural identity). Life habits ensure the person’s survival and well-being throughout his or her lifetime.

Social participation corresponds to the complete realization of life habits, resulting from the interaction of personal factors (impairments, disabilities and other characteristics of the person) and environmental factors (facilitators and barriers).

A **handicap situation** (the term used in this policy is “handicapping situation”) corresponds to a reduction in the realization of life habits, resulting from the interaction of personal factors (impairments, disabilities and other characteristics of the person) and environmental factors (facilitators and barriers).

Presentation of fundamental values

Respect for human dignity

As a human being and a member of society, every person has the right to respect of their life, physical and psychological integrity, autonomy and specific characteristics. Respect for human dignity and the right to equality are among the cornerstones of justice and the systems governing rights and freedoms. They are universal and encompass formal equality, respect for diversity and rejection of discrimination and exclusion.

Equality and anti-discrimination efforts

Identical treatment is not synonymous with equal treatment. In fact, in some cases, a person must be treated differently in order to be treated equally. This applies to every handicapped person, no matter what the impairment (intellectual, motor, sensory, organic, pervasive development disorder or severe mental health problem) or the person’s age, gender, sexual orientation, ethnic or national origin, or religion. Equality is a social ideal that warrants the deployment of considerable means. The right to equality and the fight against direct, indirect or systemic discrimination are the instruments employed in the pursuit of equality. Special efforts must be made to combat intersectional discrimination. This societal ideal consists of ideas such as:

- Accommodation and treatment of a person based on his or her needs;
- Compensation for needs related to impairments, disabilities and handicapping situations, and establishment of the required services;
- Compensation for additional costs not covered by the support offered to individuals and their families;

- Legal recourse;
- Proactive social policies for reducing inequalities.

Freedom

Freedom hinges on the ability to set goals and to work towards them. The more personal and environmental resources persons have, the freer they are to choose and to enjoy a wide array of choices, and, by extension, to have the life they want. All people must have the opportunity for a successful life on their terms, whether through the search for well-being or through achievement of goals they select and cherish. These personal resources and the opportunities and constraints of the environment are determinative in the exercise of freedom. Society is duty-bound to foster as wide a range of fundamental freedoms as possible provided that the freedom of one individual does not infringe on that of others.

Solidarity and equity

In the modern world, the State is a leading player in terms of the social solidarity of all other instances within civil society, including those with an obligation to accommodate handicapped persons, such as private businesses and other civil institutions. Families and caregivers are natural agents of solidarity, and, in this capacity, they must not be left to operate unassisted and in a vacuum. The State must fulfill the responsibilities proper to it in this regard.

Equal rights can and must be ensured by society. For its part, equity is aimed at reconciling the rights and duties of all the members of a society, notably, the right to equality and the literal and figurative costs thereof in the real world. The choices made by equitable societies are consistent with the values of equality, justice and solidarity. Equity makes it possible to gauge these costs and resources required for fulfilling the needs of handicapped persons. In this way, equity allows the social integration of handicapped persons to occur in a way heedful of the situations that are specific to each individual.



**THE POLICY
IN BRIEF**

THE POLICY IN BRIEF EQU

GOAL: INCREASE THE SOCIAL PARTICIPATION OF HANDICAPPED PERSONS
LEGAL BASES: RIGHT TO EQUALITY AND PROTECTION, LEGISLATION ON DISABILITY
CONCEPTUAL BASES: DISABILITY CREATION PROCESS

EXPECTED OUTCOMES

TOWARDS SIGNIFICANT IMPROVEMENT OF THE LIVING CONDITIONS OF HANDICAPPED PERSONS

- Improve the income of handicapped persons
- Improve the health of handicapped persons
- Improve the educational level of handicapped persons
- Reduce the social isolation of handicapped persons

TOWARDS COMPLETE FULFILLMENT OF THE BASIC NEEDS OF HANDICAPPED PERSONS (EVERYDAY ACTIVITIES)

- Offer handicapped persons the possibility of fully carrying out the activities that allow them to live at home
- Offer handicapped persons the possibility of being housed adequately according to their specific needs, in a place of their choosing
- Offer handicapped persons the possibility of expressing themselves and communicating adequately with those around them, whatever means of communication are used
- Offer handicapped persons the possibility of being mobile without added accessibility, time or cost constraints, no matter the place or the means used

TOWARDS PARITY BETWEEN HANDICAPPED PERSONS AND OTHER CITIZENS IN THE EXERCISE OF SOCIAL ROLES IN CONDITIONS EQUIVALENT TO THOSE OF OTHERS

- Increase the participation of handicapped children in educational daycare services and in school environments
- Increase the participation of handicapped students at all levels of basic and continuing education
- Increase the participation of handicapped persons in the workplace, without discrimination
- Increase the participation of handicapped persons in recreational, sports, tourism and cultural activities
- Increase the civic participation of handicapped persons in their community

EVALUATION

- ➔ THROUGH EVALUATION OF EXPECTED OUTCOMES
- ➔ THROUGH INDICATORS

FOCUS OF ACTION 3 MAJOR CHALLENGES AND

FOR AN INCLUSIVE SOCIETY, THE

- Act against prejudice and discrimination
- Act against all forms of exploitation
- Devise barrier-free laws, policies and programs
- Take into account the diversity of handicapped persons
- Design accessible environments

FOR A UNIFIED AND MORE EQUITABLE SOCIETY,

- Act against the poverty of handicapped persons
- Aim for adequate compensation for handicapped persons and their families
- Increase access to, completion of and participation in education

FOR A SOCIETY THAT RESPECTS THE RIGHTS OF HANDICAPPED PERSONS AND OF THEIR FAMILIES, THE

- Make individualized and comprehensive plans
- Support the exercise of family and social roles
- Make structured accompaniment available to handicapped persons and their families

EVALUATION

THROUGH EVALUATION OF EXPECTED OUTCOMES

THROUGH INDICATORS



EQUALS IN EVERY RESPECT

HANDICAPPED PERSONS WITHIN THE NEXT 10 YEARS
LEGISLATION AS AMENDED IN 2004

11 PRIORITY THRUSTS

PRIORITIES ARE TO:

• Eliminate discrimination
• Eradicate exploitation, violence and mistreatment
• Develop policies, programs and services
• Take into account the diversity of family structures in drafting family policy
• Support family members.

IN A DIVERSE AND STABLE SOCIETY, THE PRIORITIES ARE TO:

• Support handicapped persons and their families
• Provide compensation for additional costs associated with deficiencies, limiting situations
• Ensure complementarity and coordination of programs and services.

IN RESPONDING TO THE CHOICES AND NEEDS OF HANDICAPPED PERSONS

PRIORITIES ARE TO:

• Develop coordinated service planning standard practice
• Support family and social roles by families
• Ensure that support services are accessible to handicapped persons

IMPLEMENTATION OF THE COMPREHENSIVE IMPLEMENTATION PLAN

FACTORS

GOVERNMENT COMMITMENTS

REGARDING POLICY IMPLEMENTATION

- Enhance, develop and use existing inter-sectoral coordination mechanisms
- Task the Office to spearhead and support the required inter-sectoral action
- Consider the annual action plans prescribed in section 61.1 of the Act, the National Strategy for Labour Market Integration and Maintenance of Handicapped Persons, government departments' and agencies' strategic plans, and sector-based policies and action plans as the preferred means for implementing the policy
- Task MSSS with assessing application of section 61.2 of the Act within the framework of its health impact assessments

REGARDING POLICY PROMOTION

- Promote the policy to all the players concerned in all action areas concerned.

REGARDING POLICY EVALUATION

- Recognize the policy's expected outcomes as significant changes that Québec should aim for
- Task the Office to carry out two-pronged evaluation of the policy:
 - evaluation of policy implementation through systematic monitoring of annual action plans and other government department and agency plans, policies and strategies
 - evaluation of expected outcomes through indicators
- Better document the state of social participation
- Ask the government departments and agencies concerned to submit a five-year policy evaluation summary report to the Ministère de la Santé et des Services sociaux (Office des personnes handicapées du Québec)

MEANS FOR MEETING AND IMPLEMENTING

AN INCLUSIVE SOCIETY

ACT AGAINST PREJUDICE AND DISCRIMINATION

- Public awareness
- Civic education for young people and adults
- Awareness-raising and training for anyone in direct contact with the public
- Accommodation measures and promotion of an inclusive approach
- Factoring in of cultural barriers in accommodation measures for handicapped persons from ethnocultural communities
- Documentation of the experiences of handicapped persons from First Nations communities.

ACT AGAINST ALL FORMS OF EXPLOITATION, VIOLENCE AND MISTREATMENT

- Inform and train handicapped persons, their families and significant others
- Design action tailored to the everyday lives of handicapped persons and adapt it accordingly
- Monitor the quality of intervention in public living environments such as residences, shelters, or other similar institutions and in private caregiving situations
- Implement and promote the recourse provided under existing legislative provisions

DEVISE BARRIER-FREE LAWS, POLICIES, PROGRAMS AND SERVICES

- Implement and comply with existing legislative provisions
- Enforce the impact clause
- Awareness and training of staff who draft public legislation, policies and programs

TAKE INTO ACCOUNT THE DIVERSITY OF FAMILY STRUCTURES IN DRAFTING FAMILY POLICY

- Bring the various stakeholders together
- Support for innovation given the new face of society and of the family

DESIGN ACCESSIBLE ENVIRONMENTS

- Improve physical accessibility
- Improve accessibility to transportation infrastructure
- Improve accessibility to means of communication
- Take the needs of handicapped persons into account in designing consumer products

A UNIFIED AND MORE EQU

ACT AGAINST THE POVERTY OF H

- Concerted action against p
- Greater income support
- Fewer disparities in terms

AIM FOR ADEQUATE COMPENSAT WITH DEFICIENCIES, IMPAIRMEN

- Full compensation of gene
- Non-income based compen
- Improved tax measures tha their families and significa
- An improved public prescri

INCREASE ACCESS TO, COMPLEM OF PROGRAMS AND SERVICES

- Improved general access to
- Improved access to and ad
- Strengthening of the fit be



ING CHALLENGES G ACTION PRIORITIES

STABLE SOCIETY

HANDICAPPED PERSONS AND OF THEIR FAMILIES

poverty and social exclusion

of income support

ION FOR ADDITIONAL COSTS ASSOCIATED

TS AND HANDICAPPING SITUATIONS

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at more directly concern handicapped persons,

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ENTARITY AND COORDINATION

o plans, programs and services

aptation of current services

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A SOCIETY THAT RESPECTS THE CHOICES AND NEEDS OF HANDICAPPED PERSONS AND OF THEIR FAMILIES

MAKE INDIVIDUALIZED AND COORDINATED SERVICE PLANNING STANDARD PRACTICE

- Service program use by all players
- A harmonized vision of the service program and of the terminology used
- Confidentiality by all players
- A mixed model for service program coordination
- Rules of consent for designating a service program coordinator
- Recognition of the contribution of families and other natural caregivers to the planning and coordination of services

SUPPORT THE EXERCISE OF FAMILY AND SOCIAL ROLES BY FAMILIES

- Improve the support offered to families
- Innovation with a view to gender equality

MAKE STRUCTURED ACCOMPANIMENT SERVICES ACCESSIBLE TO HANDICAPPED PERSONS AND THEIR FAMILIES

- Accompaniment service development in every region
- Harmonization of accompaniment practices
- Recognition of accompaniment needs in the individualized and coordinated planning of services
- Better training and wages for attendants