

# FAMILY SUPPORT GUIDE

FOR THE PARENTS  
OF A CHILD OR OF  
AN ADULT WITH A  
DISABILITY



## PART ONE

>>> IDENTIFYING YOUR NEEDS



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OF A CHILD OR OF  
AN ADULT WITH A  
DISABILITY



## PART ONE

>>> IDENTIFYING YOUR NEEDS

OFFICE DES PERSONNES  
HANDICAPÉES DU QUÉBEC

*pooling*  
our strengths

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The content of this publication was written by the  
Office des personnes handicapées du Québec.

**This document is available in adapted media formats upon request.**

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Office des personnes handicapées du Québec  
309, rue Brock, Drummondville (Québec) J2B 1C5  
Phone: 1 800 567-1465  
TTY: 1 800 567-1477  
Email: [aide@ophq.gouv.qc.ca](mailto:aide@ophq.gouv.qc.ca)  
Website: [www.ophq.gouv.qc.ca](http://www.ophq.gouv.qc.ca)

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## >>> FOREWORD

The Family Support Guide, presented in two parts, is designed to help the parents of a child or an adult with a disability determine their service needs, for example, childcare or sitting services, home support, and transportation, as well as to identify the resources in response to these needs.

This is Part One of the guide. We urge parents to use it to prepare for meetings with the staff of institutions under the responsibility of **the integrated health and social services centre (CISSS)** or the **integrated university health and social services centre (CIUSSS)** of their region.

Part Two is entitled *Resources*. It provides the name and contact information of the resources, by region and service type, that offer services to people with disabilities. It also provides a brief description of the services as well supplementary information such as the name of the organizations from which you can obtain support or additional information. (Part Two in French only)

### NOTE:

The CISSS or CIUSSS, depending on the region, groups and coordinates the various regional health and social services institutions, including local community service centres (CLSCs), health and social services centres (CSSSs), rehabilitation centres for physical disabilities (CRDPs), rehabilitation centres for intellectual disabilities and pervasive developmental disorders (CRDITEDs), residential and long-term care centres (CHSLDs) and hospital centres (CHs), which remain the service providers for the population and the gateway to general health and social services.

To find the CISSS or CIUSSS institution nearest you in your region, contact **Info-Santé** by phone at **811**.

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## >>> SERVICES OFFERED BY THE OFFICE

The role of the **Office des personnes handicapées du Québec** is to inform, advise, assist and lobby on behalf of people with disabilities and their families and caregivers. Its services cover all areas of education, work and social integration of people with any kind of disability. More specifically, its services consist in:

- supporting and guiding people with disabilities and their families and caregivers in order to facilitate access to services and programs;
- advising people with disabilities and their families and caregivers to determine how they can obtain services and programs (drawing up of an intervention plan or an individualized service program);
- assisting people with disabilities and their families and caregivers in their dealings with service providers.

### FOR SERVICES OR ASSISTANCE

Office des personnes handicapées du Québec

Direction des services aux personnes handicapées et à leur famille

Phone: 1 800 567-1465

TTY: 1 800 567-1477

Email: [aide@ophq.gouv.qc.ca](mailto:aide@ophq.gouv.qc.ca)

Website: [www.ophq.gouv.qc.ca](http://www.ophq.gouv.qc.ca)

## >>> OTHER GUIDES PUBLISHED BY THE OFFICE

There are many programs and measures to help people with disabilities, their families and their caregivers financially. For example, you may be eligible for the home support program, home or vehicle adaptation programs or adapted transportation services. For your children, you are entitled to child assistance from Retraite Québec, but you may also qualify for the supplement for handicapped children, the supplement for handicapped children with exceptional care needs or the social assistance or social solidarity programs.

For a comprehensive picture of the tax measures and programs for people with disabilities, their families and caregivers, the Office has published two other guides—the *Guide to Programs for People with Disabilities, Their Families and Caregivers* and the *Guide des mesures fiscales provinciales et fédérales à l'intention des personnes handicapées, de leur famille et de leurs proches*. Take a look!

### **Guide to Programs for People with Disabilities, Their Families and Caregivers**

The purpose of this guide is to facilitate access to information on Québec programs for people with disabilities, their families and caregivers. It presents programs related to income support, home support, housing, employment, technical aids, childcare services, education and transportation, as well as recreation, sport, culture and community living. It also covers the main compensation plans in Québec for people with disabilities.

A fact sheet on each program contains a description of the program, the main eligibility requirements, the available assistance and the application procedure, as well as useful links for additional information.



**Guide des mesures fiscales provinciales et fédérales  
à l'intention des personnes handicapées, de leur famille  
et de leurs proches**

This guide puts information on provincial and federal tax measures at your fingertips. The measures are divided into five sections: non-refundable tax credits, refundable tax credits, tax deductions, tax exemptions and rebates, and other special measures for people with disabilities.

A fact sheet for each measure provides, among other things, a description of the measure, the eligibility requirements, how to claim the measure and any conditions that may apply. (Guide in French only)

These guides can be viewed online at [www.ophq.gouv.qc.ca/publications](http://www.ophq.gouv.qc.ca/publications).

**TO ORDER A FREE COPY OF THE GUIDES**

Office des personnes handicapées du Québec

Phone: 1 800 567-1465

TTY: 1 800 567-1477

Email: [publication@ophq.gouv.qc.ca](mailto:publication@ophq.gouv.qc.ca)

Website: [www.ophq.gouv.qc.ca/commanderguides](http://www.ophq.gouv.qc.ca/commanderguides)

# >>> IDENTIFYING YOUR NEEDS

## INFORMATION NEEDS

The purpose of this section is to help you as parents identify your information needs as they relate to the situation of your child with a disability.

- You want details on your child's diagnosis, disabilities, impairments and abilities.
- You want to know about the services that exist and possible financial assistance.
- You want to know what your and your child's rights are if you are denied a service or are dissatisfied with one.
- You want to meet families experiencing a situation similar to yours.

### CONCERNING THE DIAGNOSIS

- We want more information, more specific information or another medical opinion.

### CONCERNING YOUR CHILD'S DISABILITY OR IMPAIRMENT

- We want to find out more about our child's disability or impairment, the cause and the short-term and long-term consequences.

### CONCERNING YOUR CHILD'S ABILITIES

- We need more information about our child's abilities and potential to develop and learn.

### CONCERNING SERVICES AND FINANCIAL ASSISTANCE

- We want to know which services are offered, existing organizations and the financial assistance available for our child and our family.

## CONCERNING ASSOCIATIONS

- We would like to know which associations there are for people with disabilities or for their parents and if they can help us.

## CONCERNING RIGHTS ADVOCACY

- We want information about our rights and those of our child with a disability.

## ADDITIONAL INFORMATION

### DIAGNOSIS

You can ask a physician for a medical opinion. If you do not know any physicians, you can ask an association for the parents of children with disabilities for help. They may be able to refer you to physicians with the right qualifications.

### THE DISABILITY OR IMPAIRMENT

Ask a clinical professional (e.g. physician, psychologist, occupational therapist) to give you information about your child's disability or impairment. The staff at integrated health and social services centre (CISSS) or integrated university health and social services centre (CIUSSS) institutions, and associations for people with disabilities or for their parents may also provide information on this subject.

You can also go to the *Services accessibles* website, which features definitions and the characteristics specific to each kind of impairment, along with advice about communicating and interacting with people with disabilities, at [www.formation.ophq.gouv.qc.ca](http://www.formation.ophq.gouv.qc.ca). Website in French only.

### SERVICES AND FINANCIAL ASSISTANCE

The staff at CISSS or CIUSSS institutions in your region, the Office des personnes handicapées du Québec, as well as associations for people with disabilities or for their parents can provide information.

## ORGANIZATIONS

You can obtain information about associations for people with disabilities or for their parents by contacting regional umbrella organizations for people with disabilities, a CISSS or CIUSSS institution in your region or the Office des personnes handicapées du Québec.

## FOR ASSISTANCE

Office des personnes handicapées du Québec  
Direction des services aux personnes handicapées et à leur famille  
Phone: 1 800 567-1465  
TTY: 1 800 567-1477  
Email: aide@ophq.gouv.qc.ca

*Also see Part Two, RESOURCES, in the sleeve at the end of the Guide.  
(Part Two in French only)*

## >>> NOTES

INDICATE THE INFORMATION YOU NEED OR THE SUBJECTS YOU WOULD LIKE TO DISCUSS.



## PSYCHOSOCIAL SUPPORT NEEDS

The purpose of this section is to help you as parents identify your psychosocial support needs and those of the members of your family.

Why bring up psychosocial support?

BECAUSE the comments, attitudes and way that members of your own family, your friends, physicians or health staff express themselves may affect your morale.

BECAUSE at times you may feel guilty and feel that you are not doing enough for your child.

BECAUSE you are at risk for exhaustion due to the situations you have to deal with.

BECAUSE the situation can become difficult to cope with for a time.

As a result, it is possible that you may need psychological help or support to make sense of it all.

You need to be psychologically healthy to be able to meet the needs of your child with a disability and those of the other members of your family.

### CONCERNING DAILY LIFE WITH YOUR CHILD WITH A DISABILITY

- We need support because it is becoming more difficult right now and we feel drained.

### CONCERNING THE ATMOSPHERE AT HOME

- We need support because the atmosphere at home is deteriorating.

### CONCERNING OTHER MEMBERS OF OUR FAMILY

- We need support because our other children are reactive regarding the situation of their sibling with a disability.
- We need support because we are having trouble responding both to the needs of our child with a disability and those of the other members of our family.

### CONCERNING FAMILY RELATIONSHIPS AND FRIENDSHIPS

- We need support because we have less and less contact, or no contact at all, with family and friends because we have a child with a disability.

## ADDITIONAL INFORMATION

Various organizations can provide psychosocial support based on the needs you have identified.

### **COMMUNITY ORGANIZATIONS**

Community organizations offer listening, mutual assistance and support services, depending on the region. It is proven that talking with other people who are experiencing the same problems as you, or who did in the past, can help you overcome your isolation and dispel your worries. Associations for people with disabilities also offer support to other members of the family, in particular by organizing discussion groups for them.

### **CISSS OR CIUSSS INSTITUTIONS**

Most integrated health and social services centre (CISSS) or integrated university health and social services centre (CIUSSS) institutions in your region offer specialized professional social services free of charge. They can help you solve the problems and difficulties you encounter.

Educational institutions can also provide psychosocial support services within the context of student education.

## FOR ASSISTANCE

Office des personnes handicapées du Québec  
Direction des services aux personnes handicapées et à leur famille  
Phone: 1 800 567-1465  
TTY: 1 800 567-1477  
Email: aide@ophq.gouv.qc.ca

*Also see Part Two, RESOURCES, in the sleeve at the end of the Guide.  
(Part Two in French only)*

## >>> NOTES

INDICATE THE NEEDS YOU WANT TO DISCUSS OR ANY OTHER QUESTIONS CONCERNING PSYCHOSOCIAL SUPPORT:



## CHILDCARE NEEDS

The purpose of this section is to help you as parents identify your childcare needs for your child with a disability so that you can achieve life/work balance and carry out your daily activities like any other person who has family responsibilities. There are three types of childcare.

**Educational childcare services** for children five years old and younger.

**School childcare services** for preschool and elementary-level students.

**Supervision services** for students between 12 to 21 years of age who attend secondary school and who, because of their impairment, cannot be at home alone outside of classroom hours.

The idea here is to identify your childcare needs based on your activities outside the home. For example, working, taking classes, recreational activities, or going grocery shopping are some of the reasons why you may need any of these different kinds of childcare for your child with a disability.

### DETERMINING OUR CHILDCARE NEEDS

#### Section 1 – Identifying childcare needs

##### **DURING THE WEEK** (Monday to Friday)

- Regular daytime (work or regular day activity)
- In the morning before family members leave for the day (family members leave at different times)
- At lunch hour
- In the afternoon (family members get home at different times)
- Other: \_\_\_\_\_



## **DURING THE YEAR**

- On pedagogical days
- During spring break
- During summer
- Other: \_\_\_\_\_

## **OUR USUAL NETWORK**

- We use an educational childcare service.
- We use a school childcare service.
- We use a supervision service.
- We have someone come in to watch our child.
- We use an external childcare service.
- We plan our outings so that one of us (parents) stays home with our child with a disability.
- Our other children take care of him/her when we are away from home.
- Members of our family watch our child.
- Our friends or neighbours watch our child.

## **RECRUITING AND PAYING CHILDCARE PROVIDERS**

- We do not want to or can no longer rely on our children, friends, or members of the family to watch our child with a disability.
- We need help finding an educational childcare service.
- We need help finding a school childcare service.
- We need help finding a supervision service.
- We need help training someone to care for our child at home.
- We pay for childcare out of pocket.
- We need financial assistance for childcare services.

## Section 2 – Calculating our childcare needs

Simply indicate the number of required hours and days in the appropriate boxes.

### NUMBER OF HOURS PER REGULAR WEEK (Monday to Friday)

- |  |                                  |
|--|----------------------------------|
| <input type="checkbox"/> Morning                     | _____ hours X _____ days = _____ |
| <input type="checkbox"/> Noon hour                   | _____ hours X _____ days = _____ |
| <input type="checkbox"/> Afternoon                   | _____ hours X _____ days = _____ |
| <input type="checkbox"/> Full day or part of the day | _____ hours X _____ days = _____ |

TOTAL HOURS PER REGULAR WEEK =

### NUMBER OF CHILDCARE HOURS PER YEAR

TOTAL PER YEAR: \_\_\_\_\_ hours X \_\_\_\_\_ weeks =

## ADDITIONAL INFORMATION

### ORGANIZATIONS OFFERING CHILDCARE

You may contact the childcare centre umbrella group in your region, the Association des garderies privées du Québec or the home childcare coordinating office for help finding an organization that offers childcare services.

### REDUCED CONTRIBUTION SPACE IN EDUCATIONAL CHILDCARE SERVICES

*La Place 0-5* is Québec's centralized waiting list for registering your child in a childcare service with access to a reduced contribution space.

To register, go to the *La Place 0-5* website at [www.laplace0-5.com](http://www.laplace0-5.com).

## **SCHOOL CHILDCARE SERVICES**

To have your child with a disability registered in a school childcare service, you must talk to the school principal at enrolment time.

You may also contact Intégration sociale des enfants handicapés en milieu de garde.

Phone: 450 646-2714

Email: [info@isehmg.org](mailto:info@isehmg.org)

Website: [www.isehmg.org](http://www.isehmg.org)

## **SUPERVISION SERVICES**

Check with the school board or the principal of the secondary school attended by your child to find out whether the school provides supervision services.

## **SUPPORT THE ORGANIZATIONS THAT MEET YOUR CHILDCARE NEEDS**

You can write a note about your child to the personnel of the organizations that offer childcare services. For example, the note could summarize your child's special needs, preferences, what he or she likes or dislikes and what you can or cannot do with him or her. Ask for the note to be put in your child's file.

You can also complete the **TO KNOW MY CHILD BETTER** fact sheet at the end of this guide and ask that it be added to the file.

## OBTAINING FINANCIAL ASSISTANCE FOR EDUCATIONAL CHILDCARE SERVICES

Financial assistance may be available to help your child obtain childcare services through the supplement for handicapped children or the supplement for handicapped children with exceptional care needs programs managed by the Ministère de la Famille.

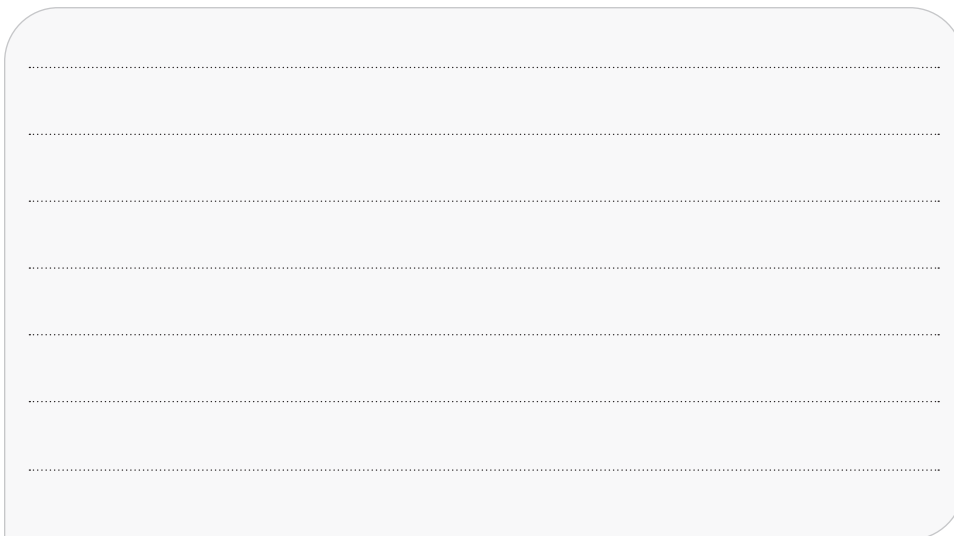
## FOR ASSISTANCE

Office des personnes handicapées du Québec  
Direction des services aux personnes handicapées et à leur famille  
Phone: 1 800 567-1465  
TTY: 1 800 567-1477  
Email: aide@ophq.gouv.qc.ca

*Also see Part Two, RESOURCES, in the sleeve at the end of the Guide.  
(Part Two in French only)*

## >>> NOTES

INDICATE THE NEEDS YOU WANT TO DISCUSS OR ANY OTHER QUESTIONS CONCERNING CHILDCARE SERVICES.



## SITTING SERVICE NEEDS

The purpose of this section is to help you as parents identify your sitting service needs for your child with a disability so that you can achieve life/work balance and carry out your daily activities like any other person who has family responsibilities.

**Sitting services** consist of the provision of someone who can stay with the person with a disability who cannot remain alone. This enables the parent to leave the house occasionally for various everyday activities.

The idea here is to identify your sitting needs based on your activities outside the home. For example, working, taking classes, recreational activities, or going grocery shopping are some of the reasons why you may need any of these different kinds of services for your child with a disability.

### DETERMINING OUR SITTING NEEDS

#### Section 1 – Identifying sitting needs

##### **DURING THE WEEK** (Monday to Friday)

- Regular daytime (work or regular day activity)
- In the morning before family members leave for the day (family members leave at different times)
- In late afternoon (family members get home at different times)
- In the evening (regular evening work or activity)
- At night (regular night work)
- Day or night, occasionally (hobbies or other activities)
- Other: \_\_\_\_\_

## WEEKENDS

- Day (work)
- Evening (work)
- Night (work)
- Day or night, occasionally

## DURING THE YEAR

- On pedagogical days
- During summer
- On statutory holidays

## OUR USUAL NETWORK

- We have someone come in to watch our child.
- We use an external sitting service.
- We plan our absences so that one of us (parents) stays home with our child with a disability.
- Our other children take care of him/her when we are away from home.
- Members of our family watch our child.
- Our friends or neighbours watch our child.

## RECRUITING AND PAYING SITTERS

- We do not want to or can no longer want to rely on our children, friends, or members of the family to watch our child with a disability.
- We need help finding a sitting service.
- We need help training someone to home-sit our child.
- We pay for sitting out of pocket.
- We have financial assistance from the home support services for caregivers program.
- We need financial assistance for the extra costs for sitting services for our child with a disability.

## Section 2 – Calculating our sitting needs

Simply indicate the number of required hours and days in the appropriate boxes.

### A – NUMBER OF HOURS PER DAY REGULARLY

- Morning \_\_\_\_\_ hours X \_\_\_\_\_ days = \_\_\_\_\_
- Noon hour \_\_\_\_\_ hours X \_\_\_\_\_ days = \_\_\_\_\_
- Late afternoon \_\_\_\_\_ hours X \_\_\_\_\_ days = \_\_\_\_\_
- Evening, regularly \_\_\_\_\_ hours X \_\_\_\_\_ days = \_\_\_\_\_
- Full day or half day \_\_\_\_\_ hours X \_\_\_\_\_ days = \_\_\_\_\_
- Other \_\_\_\_\_ hours X \_\_\_\_\_ days = \_\_\_\_\_

**Total A** hours per regular weekday = \_\_\_\_\_

**ANNUAL TOTAL A:** \_\_\_\_\_ hours per week X \_\_\_\_\_ weeks =

### B – NUMBER OF HOURS PER WEEKEND REGULARLY

- Day \_\_\_\_\_ hours X \_\_\_\_\_ days = \_\_\_\_\_
- Evening \_\_\_\_\_ hours X \_\_\_\_\_ days = \_\_\_\_\_
- Other \_\_\_\_\_ hours X \_\_\_\_\_ days = \_\_\_\_\_

**Total B** hours per weekend regularly = \_\_\_\_\_

**ANNUAL TOTAL B:** \_\_\_\_\_ hours per week X \_\_\_\_\_ weeks =

### C – NUMBER OF HOURS PER WEEK AND PER WEEKEND OCCASIONALLY

- Occasionally \_\_\_\_\_ hours X \_\_\_\_\_ days = \_\_\_\_\_

**ANNUAL TOTAL C:** \_\_\_\_\_ hours per week X \_\_\_\_\_ weeks =

## D – DAYS OFF DURING THE YEAR

- |   |                                  |
|---|----------------------------------|
| <input type="checkbox"/> Pedagogical days   | _____ hours X _____ days = _____ |
| <input type="checkbox"/> Spring break       | _____ hours X _____ days = _____ |
| <input type="checkbox"/> Statutory holidays | _____ hours X _____ days = _____ |
| <input type="checkbox"/> Christmastime      | _____ hours X _____ days = _____ |
| <input type="checkbox"/> Other              | _____ hours X _____ days = _____ |

**Total D** number of days off during the year = \_\_\_\_\_

**ANNUAL TOTAL D:** \_\_\_\_\_ hours per week X \_\_\_\_\_ weeks =

## NUMBER OF SITTING HOURS PER YEAR

TOTAL A  + TOTAL B  + TOTAL C  + TOTAL D  =

## ADDITIONAL INFORMATION

### ORGANIZATIONS OFFERING SITTING SERVICES

Depending on the region, organizations offer sitting services or have banks of people trained to respond adequately to the needs of children with disabilities.

### SITTER TRAINING

Depending on the region, community organizations offer training to sitters so they are able to respond to the needs of your child with a disability. If you have already recruited someone you trust, that person could get training to improve his or her skills.

### SUPPORT THE ORGANIZATIONS THAT MEET YOUR SITTING NEEDS

You can write a note about your child to the personnel of the organizations that offer sitting services. For example, the note could summarize your child's special needs, preferences, what he or she likes or dislikes and what you can or cannot do with him or her. Ask for the note to be put in your child's file.



You can also complete the **TO KNOW MY CHILD BETTER** fact sheet at the end of this guide and ask that it be added to the file if need be.

### **OBTAINING FINANCIAL ASSISTANCE FOR SITTING SERVICES**

You can obtain financial assistance under the home support services for caregivers program. You must apply at an integrated health and social services centre (CISSS) or integrated university health and social services centre (CIUSSS) institution in your region.

### **FOR ASSISTANCE**

Office des personnes handicapées du Québec  
Direction des services aux personnes handicapées et à leur famille  
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Email: aide@ophq.gouv.qc.ca

*Also see Part Two, RESOURCES, in the sleeve at the end of the Guide.  
(Part Two in French only)*

## **>>> NOTES**

INDICATE THE NEEDS YOU WANT TO DISCUSS OR ANY OTHER QUESTIONS CONCERNING SITTING SERVICES.

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## RESPITE SERVICE NEEDS

The purpose of this section is to help you as parents identify your respite service needs, time for you to rest and refuel away from your child with a disability. You may need respite time because you feel particularly tired or you want to avoid burnout. If this is the case, the format for giving yourself this respite time varies.

- Your child with a disability may spend a few hours or days at an external organization.
- Someone can sit with your child at home while you leave for a certain time.
- Your child with a disability may be enrolled at a day camp or summer camp.

You can also synchronize respite time with your child's organized recreational activities.

### DETERMINING OUR RESPITE SERVICE NEEDS

#### Section 1 – Identifying respite service needs

##### ABOUT YOUR CURRENT SITUATION

- We would need a period of respite.
- We would need regular respite periods throughout the year.
- We would need respite, but we have trouble leaving our child with someone else for a few days.
- We would need respite time so that we have time for our other children.
- We would need respite time so that our other children can have quality time with us.

**ABOUT OUR NATURAL RESPITE NETWORK**

- Our family home sits our child when we ask them to.
- Our friends or acquaintances home sit our child when we ask them to.
- We do not know anyone who can give us respite time.
- We do not want to or can no longer ask our family or friends for respite time.

**ABOUT THE ORGANIZATIONS OFFERING RESPITE SERVICES**

- We do not know any respite service.
- We do not have the financial means to use an organization that offers respite services.
- We use a respite service and have financial assistance for it.
- We use a respite service, but we have no financial assistance for it.
- For some of our respite service needs, we have to pay out of pocket.
- We are waiting for respite services.
- Other: .....

Describe – Other situations related to your respite needs.

.....

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**ABOUT THE APPROPRIATE RESPITE SERVICES**

- A respite facility would suit.
- A vacation camp would suit.
- A day camp would suit.
- Sitting services would suit.
- I don't know. I would like to discuss it.
- Other:.....

Describe – Other appropriate services related to your respite needs.

.....

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.....

.....

Please complete the description of your respite needs by specifying the following :

- What other responsibilities do you have because of the specific characteristics of your child with a disability?

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- What do these specific characteristics entail for you?

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.....

- What specific characteristics of your **child with a disability** have a significant impact on your need for respite?

.....

.....

.....

- What specific characteristics of your **family** have a significant impact on your need for respite?

.....

.....

.....

## Section 2 – Calculation of respite service needs

Simply indicate, depending on the case, the desired number of hours and days in the appropriate boxes.

### OUR RESPITE SERVICE NEEDS

- Number of respite weekends during the year: \_\_\_\_\_
- Number of hours, days or other format during the year: \_\_\_\_\_

### PARENTS' RESPITE AND CHILD'S RECREATIONAL ACTIVITIES

- Number of days your child attends a summer camp (with sleepover): \_\_\_\_\_
- Number of weeks your child attends a summer day camp (without sleepover): \_\_\_\_\_

## ADDITIONAL INFORMATION

### **ORGANIZATIONS OFFERING RESPITE SERVICES**

Associations of parents of children with disabilities or organizations offer respite services, day camps, day activities or vacation camps specializing in children or adults with disabilities. Staff are trained to respond to their needs.

Most municipalities have summer day camps for all the children within their territory. The municipalities must establish accommodation measures to facilitate the integration of children with disabilities. Ask your city or municipality or the regional sports and recreation unit in your community.

### **ORGANIZATIONS OFFERING SPECIALIZED RESPITE SERVICES**

Some integrated health and social services centre (CISSS) or integrated university health and social services centre (CIUSSS) institutions offer respite services in order to respond to your child's needs if the child needs more specialized care. You must apply to the CISSS or CIUSSS in your region.

### **SUPPORT THE ORGANIZATIONS THAT MEET YOUR RESPITE NEEDS**

You can write a note about your child to the personnel of the organizations that offer respite services. For example, the note could summarize your child's special needs, preferences, what he or she likes or dislikes and what you can or cannot do with him or her. Ask for the note to be put in your child's file.

You can also complete the **TO KNOW MY CHILD BETTER** fact sheet at the end of this guide and ask that it be added to the file.

## OBTAINING FINANCIAL ASSISTANCE FOR RESPITE SERVICES

There is financial assistance available to help you pay for respite services. You must apply at an integrated health and social services centre (CISSS) or integrated university health and social services centre (CIUSSS) institution in your region. Certain organizations can also respond to the special financial needs of families with a child with a disability.

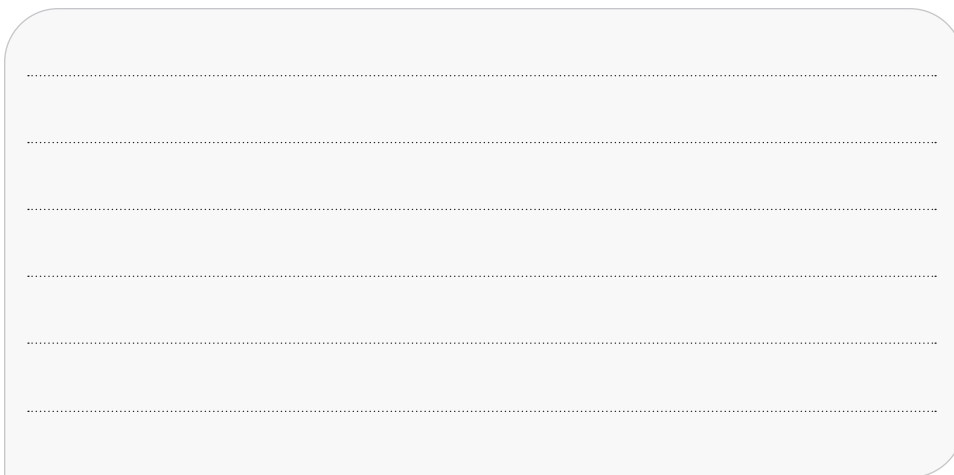
## FOR ASSISTANCE

Office des personnes handicapées du Québec  
Direction des services aux personnes handicapées et à leur famille  
Phone: 1 800 567-1465  
TTY: 1 800 567-1477  
Email: aide@ophq.gouv.qc.ca

*Also see Part Two, RESOURCES, in the sleeve at the end of the Guide.  
(Part Two in French only)*

## >>> NOTES

INDICATE THE NEEDS YOU WANT TO DISCUSS OR ANY OTHER QUESTIONS CONCERNING RESPITE SERVICES.



## DAY ACTIVITY OR EMPLOYABILITY DEVELOPMENT NEEDS

The purpose of this section is to help you as parents identify community day activity or employability development needs for your child with a disability who is 21 years old and over and no longer attends school.

The goal of having your child participate in such activities is three-pronged: giving him or her the opportunity to develop his or her potential and to socialize with people outside the family; enable him or her to maintain his or her ability in terms of functional autonomy while learning social skills; and enabling you to carry out your daily activities and blending your family life and work while your adult child carries out meaningful activities.

Please identify the day activities that foster your child's social participation or employability development. Then indicate the number of days corresponding to the identified needs in the space for that purpose on the last page of this guide.

### DAY ACTIVITIES FOR THOSE 21 AND OVER LIVING AT HOME

Our child with a disability:

- does not attend an educational institution, workplace or day centre;
- cannot be left at home alone unsupervised while we are at work;
- can stay home alone during the day but does not have any structured or organized activities;
- can stay home alone but needs stimulation or social contact;
- stays home nights and weekends;
- attends a day centre regularly;



- attends a day centre occasionally;
- has the potential to develop his or her autonomy;
- has already done a workplace internship;
- has already had day activities;
- other: .....

Describe – Other constraints or specific characteristics related to day activities.

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**EMPLOYABILITY DEVELOPMENT ACTIVITIES FOR  
THOSE 21 AND OVER LIVING AT HOME**

Our child with a disability:

- has the potential to develop his or her autonomy;
- has already done a workplace internship;
- has already had day activities;
- has already done volunteer work;
- has already looked for a job;
- has already worked during the school year or in the summer;
- receives services from an organization to help him or her look for a job or a workplace internship;
- other: .....

Describe – Other constraints or specific characteristics related to day activities.

.....

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.....

## ABOUT OUR CURRENT SITUATION

- Our child with a disability needs to be outside the home regularly, to have stimulating activities and to socialize with people outside the family.

## ADDITIONAL INFORMATION

### DAY ACTIVITIES

Depending on the regions, certain community organizations, integrated health and social services centre (CISSS) or integrated university health and social services centre (CIUSSS) institutions and the Office des personnes handicapées du Québec can refer you to such organizations.

### EMPLOYABILITY DEVELOPMENT ACTIVITIES

For information about organizations, programs and services that foster the occupational integration of people with disabilities, you can visit the website of the Ministère du Travail, de l'Emploi et de la Solidarité sociale at [www.emploi.quebec.gouv.qc.ca](http://www.emploi.quebec.gouv.qc.ca).

You can also contact the Regroupement des organismes spécialisés pour l'emploi des personnes handicapées by email at [info@roseph.ca](mailto:info@roseph.ca).

## FOR ASSISTANCE

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## EMERGENCY TEMPORARY CARE SERVICE NEEDS

The purpose of this section is to help you as parents identify your emergency temporary care service needs in unforeseen or emergency situations that may temporarily affect your ability to take care of your child with a disability. Note that these services are generally of short duration (at most a few weeks long).

### ABOUT OUR SITUATION

- We have resources (for example, family, friends) for unforeseen or emergency situations.
- We have no resources for unforeseen or emergency situations.

### ABOUT ORGANIZATIONS OFFERING EMERGENCY TEMPORARY CARE SERVICES

- We want to know more about the organizations that could take care of our child with a disability in unforeseen or emergency situations.
- We need help finding an organization that offers emergency temporary care services that match our and our child's needs.

## ADDITIONAL INFORMATION

### ORGANIZATIONS OFFERING EMERGENCY TEMPORARY CARE SERVICES

Depending on the region, associations for parents with children with disabilities or organizations that offer respite service may also provide emergency temporary care facilities. These resources have staff trained to respond adequately to the needs of your child with a disability.

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## **ORGANIZATIONS OFFERING SPECIALIZED EMERGENCY TEMPORARY CARE SERVICES**

Some integrated health and social services centre (CISSS) or integrated university health and social services centre (CIUSSS) institutions offer emergency temporary care services and have the staff needed to respond to your child's needs if the child requires more specialized care. You must apply to the CISSS or CIUSSS in your region.

## **SUPPORT THE ORGANIZATIONS THAT MEET YOUR EMERGENCY TEMPORARY CARE SERVICE NEEDS**

You can write a note about your child to the personnel of the organizations that offer emergency temporary care services. For example, the note could summarize your child's special needs, preferences, what he or she likes or dislikes and what you can or cannot do with him or her. Ask for the note to be put in your child's file.

You can also complete the **TO KNOW MY CHILD BETTER** fact sheet at the end of this guide and ask that it be added to the file.

## **OBTAINING FINANCIAL ASSISTANCE FOR EMERGENCY TEMPORARY CARE SERVICES**

Under the home support services for caregivers program, you may obtain financial assistance to help with the cost of emergency temporary care services. Note that this assistance is distinct from that granted for sitting and respite services. You must contact an integrated health and social services centre (CISSS) or integrated university health and social services centre (CIUSSS) institution in your region.

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(Part Two in French only)*

## >>> NOTES

INDICATE THE NEEDS YOU WANT TO DISCUSS OR ANY OTHER QUESTIONS CONCERNING EMERGENCY TEMPORARY CARE SERVICES.



## HOME SUPPORT NEEDS

Home support services are varied. They range from personal assistance to help with housework or may consist of civic support activities, meals on wheels or help with family tasks. The purpose of these services is to help the parents of a child with a disability carry out their responsibilities as a parent. The services vary according to needs.

A person may take care of your child with a disability while you help your other children with their homework or do housework. It may also be the other way around: while you attend to your child with a disability, someone else helps your other children with their homework or does housework.

### RESPONDING TO YOUR CHILD'S NEEDS

- We need help from someone who will take care of our child with a disability while we attend to our other children or do housework.
- We need help from someone who will help our other children with their homework or do housework while we attend to our child with a disability.

### ABOUT TRAVELLING WITH YOUR CHILD

- We need help from someone when we travel with our child with a disability:
  - because of his or her behavioural problems;
  - because of the physical requirements that travel entails.

## ADDITIONAL INFORMATION

### **OBTAINING FINANCIAL ASSISTANCE FOR HOME SUPPORT SERVICES**

One of the ways you may obtain financial assistance is through the home support services program. These services may be offered directly by an integrated health and social services centre (CISSS) or integrated university health and social services centre (CIUSSS) institution in your region or by means of a subsidy you receive directly from the institution.

### **ASSISTANCE FOR CERTAIN OF YOUR CHILD'S PROBLEMS**

In some cases, the CISSS or CIUSSS in your region may assist you in dealing with your child's behavioural problems and suggest ways of handling such situations at home or while you are on the move.

Sometimes parents must help their child do home rehabilitation. A discussion with the worker concerned may enable all these different activities to be harmonized to make it easier to do them at home.

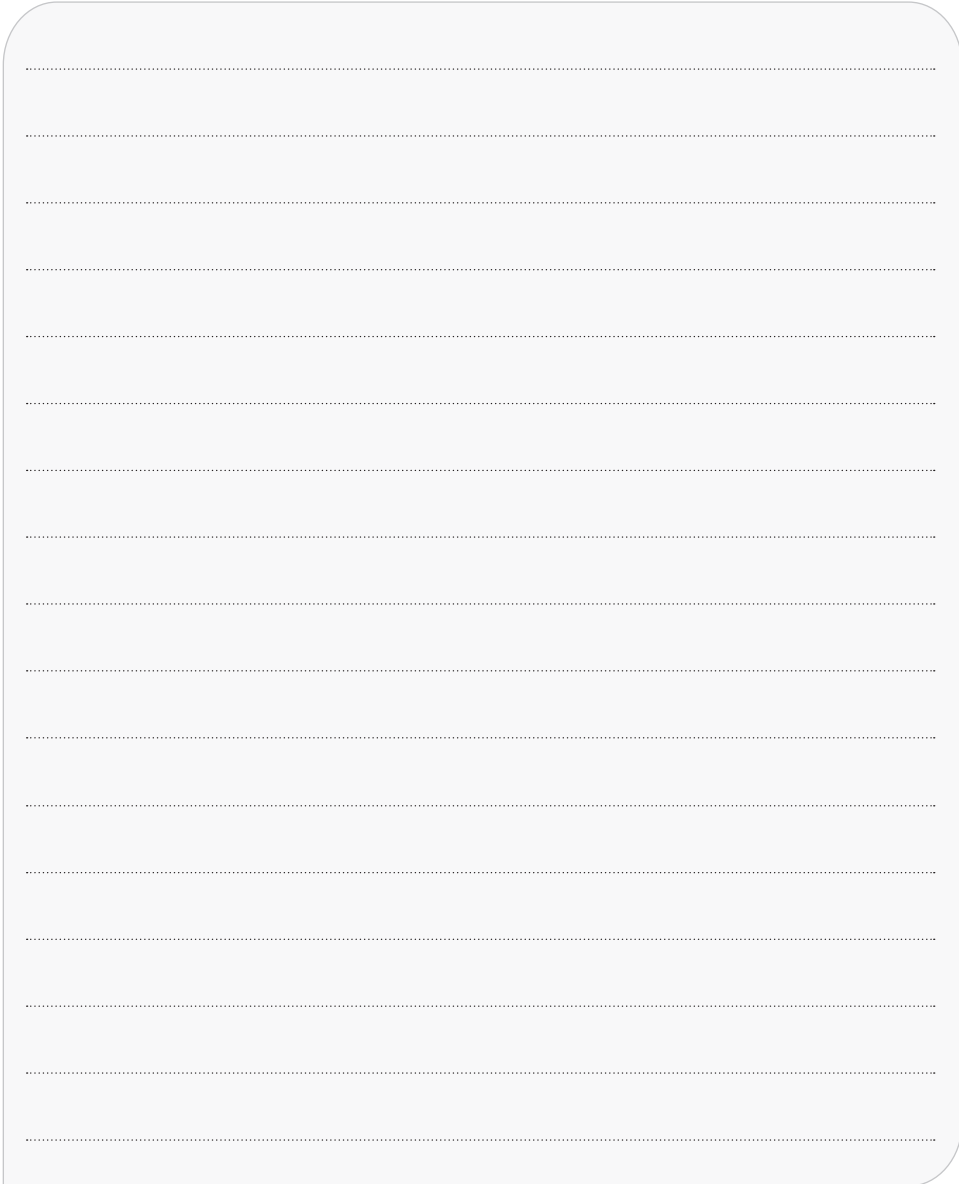
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(Part Two in French only)*

## >>> NOTES

INDICATE THE NEEDS YOU WANT TO DISCUSS OR ANY OTHER QUESTIONS CONCERNING HOME SUPPORT SERVICES.

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## >>> YOUR NEEDS ARE IDENTIFIED

You have just finished determining your family support needs. You can now begin the process of finding ways to meet your needs. By referring to Part Two, *RESOURCES*, in the sleeve at the end of the guide, you can identify the organizations you can contact for services, financial assistance or further information.

An integrated health and social services centre (CISSS) or integrated university health and social services centre (CIUSSS) institution in your region will be able to meet many of your home support needs, especially concerning your application for financial assistance for sitting, respite or emergency temporary care services.

You can also obtain information, referral and support services from the Office des personnes handicapées du Québec to help you with the process.

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### **DON'T FORGET!**

- Bring your guide with you when your family support needs are assessed or reassessed.
- Use it as a starting point or as a way to jog your memory so that you keep the discussion focused on your needs and concerns.
- You can be accompanied by someone of your choosing when you meet with the personnel of a CISSS or CIUSSS institution.

## >>> YOUR RIGHT TO RECOURSE

**IF YOU ARE DISSATISFIED WITH A DECISION OR WITH SERVICES YOU RECEIVED, YOU HAVE THE RIGHT TO:**

- Use the recourse mechanisms available within government departments and agencies.
- File a complaint with the Service Quality and Complaints Commissioner of the integrated health and social services centre (CISSS) or integrated university health and social services centre (CIUSSS) in your region.

**YOU CAN OBTAIN ASSISTANCE OR SUPPORT IN FILING AN OFFICIAL COMPLAINT FROM:**

- the complaint assistance and support centre in your region;
- the Office des personnes handicapées du Québec;
- certain associations, if they are not involved in the service offer.

### **DON'T FORGET!**

Before beginning the official complaint process, often it is better to talk with the worker involved in order to find a solution.

# >>> TO KNOW MY CHILD BETTER

## FACT SHEET

The purpose of this fact sheet is to help you as parents provide the people who work with your child (for example, childcare, sitting, respite and emergency services), with a portrait of your child's health, physical condition, assistance needs, elements of his or her behaviour and ability to communicate.

We encourage you to photocopy this fact sheet and to give the completed copy to the personnel concerned in order to help them know your child better and provide you with the best possible support.

### HEALTH AND PHYSICAL CONDITION

Our child with a disability:

- is generally in good health;
- has health problems requiring frequent visits to the doctor;
- has health problems that can require hospitalizations;
- has impairments that require interventions by specialists (for example, speech therapist, occupational therapist);
- needs help eating and with elimination, that can involve use of tube feeding, catheters, and rectal stimulation;
- needs equipment or devices that can cause problems (for example, infections, sores);
- takes medication that can cause negative side effects;
- has uncontrolled or poorly controlled epilepsy;
- is in considerable pain;
- requires care at night (change of position, calming, other care);
- other: .....



Describe – Other constraints related to health and physical condition.

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### **ASSISTANCE NEEDS**

Our child with a disability:

- can generally get dressed and undressed, eat, drink, use the washroom, wash himself or herself, get up and go to bed on his or her own;
- can carry out these tasks on his or her own with reminders, instructions, supervision and help if needed;
- can carry out these tasks, but needs a tremendous amount of time;
- gets started only after much bargaining;
- is dependent for the vast majority of these tasks or cannot do them on his or her own;
- is increasingly difficult to lift and help during transfers;
- other: .....

Describe – Other constraints related to physical assistance needs.

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## BEHAVIOUR

Our child with a disability:

- has no behavioural problems;
- has temper tantrums or episodes of aggression;
- cries and screams during these episodes;
- gets impatient and becomes aggressive if he or she cannot be understood;
- refuses to take his or her medication or use his or her devices/equipment;
- self-mutilates often and has to be supervised;
- self-mutilates and must wear protective equipment;
- runs away if unsupervised;
- puts objects that he or she can reach in his or her mouth;
- generally does not do anything if unstimulated;
- other: .....

Describe – Other constraints related to behaviour.

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## DURING TRANSPORTATION AND OUTINGS

Our child with a disability:

- has no problems during outings or with using means of transportation;
- has behavioural problems that have to be controlled during outings or when using a means of transportation;
- has health problems or impairments that have to be taken into account during outings when using means of transportation;
- has visual or communication impairments that have to be taken into account during outings or when using means of transportation;



- has impairments related to orientation in time and space that have to be taken into account during outings or when using means of transportation;
- other: .....

Describe – Other constraints related to transportation and outings.

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### **ABILITY TO COMMUNICATE**

Our child with a disability:

- has no trouble communicating;
- has trouble understanding instructions, which have to be repeated and explained over and over;
- has trouble expressing himself or herself clearly and can be difficult to understand;
- needs interpretation (reformulation, lip reading or sign language);
- uses an assisted communication device that workers must know how to use (for example, picture board, speech-generating device, or other electronic communication device);
- other: .....

Describe – Other constraints related to communication.

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*Office des personnes  
handicapées*

**Québec**    
 

## OFFICE DES PERSONNES HANDICAPÉES DU QUÉBEC

>>> Phone: 1 800 567-1465

>>> TTY: 1 800 567-1477

>>> [aide@ophq.gouv.qc.ca](mailto:aide@ophq.gouv.qc.ca)

[www.ophq.gouv.qc.ca](http://www.ophq.gouv.qc.ca)

