

SPEAK UP!

Tips for becoming
an effective advocate.

Information compiled and presented
by Cerebral Palsy Association of BC
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May 2000

Penticton Advocacy Network

'The Advokit'

*A step-by-step guide to
effective advocacy*

FREE

*Second Printing
March 1997*

'The AdvoKit'

Funding for 'The AdvoKit' was provided by the Ministry of Social Services and the Legal Services Society of British Columbia in January 1996. Revisions to 'The AdvoKit' were made possible through funding from the Ministry for Children and Families and The Office of the Child, Youth and Family Advocate in the Province of British Columbia, March 1997.

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The Penticton Advocacy Network

'The AdvoKit' is a project of the Penticton Advocacy Network. In March 1997, the Network was representative of service providers from the following agencies:

Penticton Community Law Office
Ministry of Human Resources
Ministry for Children & Families
Penticton & District Community Resources Society
Penticton Regional Hospital
Penticton & District Retirement Service
Canadian Mental Health Association

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Introduction

Advocacy doesn't work if your house is on fire. If you are in a life-threatening situation, call 911.

If a situation you are facing has you feeling discouraged, confused or frustrated, use 'The AdvoKit' to gain some control over what is happening.

Advocates speak out when they disagree with something.

Everyone has rights and Responsibilities.

Good records are an important advocacy tool especially when there are disagreements.

Sometimes people experience difficulties dealing with an agency, 'system', or government bureaucracy.

Difficulties can arise in any number of areas. You may have to deal with housing, income assistance, health care, or some other issue. As a result of dealing with large, impersonal systems, individuals can be left feeling alone or powerless.

'The AdvoKit' provides a step-by-step action plan on how to be clear about, and go after, what you want. The suggestions in this booklet are ideas that have been used in all kind of situations. Everyone's situation is unique. Use what works for you; ignore the rest.

Pages 3 and 4 explain what advocates do and why they do it. This booklet is aimed at individuals. There are many other excellent sources of information available about how to get together with other people who are interested in the same advocacy issues as you are.

Some rights, such as human rights, are spelled out in the Canadian Charter of Rights and the Human Rights Act. Other rights and entitlements are written into government acts and regulations; an example is BC Benefits. Responsibilities go along with rights. Some rights and responsibilities to think about are listed on page 5.

Keeping accurate and detailed records of your situation is one of the most important aspects of advocacy. You will need to answer the "W5" questions: what? who? where? when? why? Page 6 gives some suggestions about record keeping.

As you work your way through the advocacy process, you will probably talk to a lot of people. Tips for effective communication are found on page 8.

Worksheets begin on page 10. Worksheets 1, 2, and 3 are a way to record what happened, whether there are any alternative solutions to your difficulties, what kind of information supports your case, and what you want to happen in this situation. With that work done, you will be able to take action.

The purpose of advocacy is to influence people who have authority to make decisions. Worksheets 4 and 5 16-19 may give you some ideas about how to communicate in person, by phone, and/or by letter. You may need to do all three, or a phone call or letter may be enough.

Did you accomplish what you set out to do? Can you live with the outcome? What worked well? What didn't work? Do you have the time and energy to carry on? The answers will be unique to each situation.

No matter what the outcome is at the end of your advocacy process, you will know that no matter how hard it was, you had the courage to try!

How you talk to people affects whether you get what you want.

Be clear about what happened and how it has affected you. Make an action plan about what to do next.

Communicate your concerns to someone who has the power to make decisions.

Evaluate the situation. If you are pleased with the outcome, congratulations. If you are not satisfied, decide if, and how, you want to carry on.

Who are advocates and what do they do?

Self-advocates

- Speak or act on their own behalf. They stand up for their rights. They decide what is best for them and take charge of getting it.
- Most people already advocate on their own behalf; they just may not call it that.

Natural Advocates

- Can be anyone, anywhere, who speaks on behalf of those who cannot speak for themselves.

Volunteer or peer advocates

- Encourage and help individuals to speak on their own behalf and act with and for individuals to resolve difficult situations.

Service providers who are advocates

- Advocate for the people who use the services of their agency; either in their own system, or in another system.

Cause advocates (also known as systems or legal advocates)

- Influence social and economic systems to bring about change for groups of people using the law and politics to establish or protect the legal rights of individuals or groups.

Why advocate?

"In Germany they came first for the Communists, and I didn't speak up because I wasn't a Communist. Then they came for the Jews, and I didn't speak up because I wasn't a Jew. Then they came for the trade unionists, and I didn't speak up because I wasn't a trade unionist. Then they came for the Catholics, and I didn't speak up because I was a Protestant.

Then they came for me, and by that time no one was left to speak up."

*Martin Niemoeller,
1892-1984*

- No one knows as much about you and what you think, feel and need as you do. If you don't speak out on your own behalf, who will?
- The only way that others are going to know that you disagree with them or that your rights or dignity have been violated is for you to tell them.
- If you don't tell the people who have the authority to make decisions in your situation that there are problems, they will assume that everything is all right.
- By speaking out, you may find out that you are not alone. By refusing to be silent, you may lead the way to changes that affect a lot of people.
- Speaking out is a big step towards keeping your self-respect and dignity. You will know that you took care of yourself, even if you do not get what you want.
- You have the right to question the "rules" you are required to live by. Just because something is a law or policy doesn't mean that it is fair or just.

Rights and responsibilities

The following rights and responsibilities refer to the relationship an advocate has with the people he or she is trying to influence.

You have the right to:	You have the responsibility to:
<ul style="list-style-type: none"> • Be treated with fairness, respect and courtesy. 	<ul style="list-style-type: none"> • Treat people with fairness, courtesy and respect.
<ul style="list-style-type: none"> • Be safe from physical and verbal abuse. • Experience and express your feelings. 	<ul style="list-style-type: none"> • Respect the right of others to be safe from physical and verbal abuse.
<ul style="list-style-type: none"> • Change your mind. 	<ul style="list-style-type: none"> • Let those you are dealing with know that you have changed your mind and find out if there will be any consequences.
<ul style="list-style-type: none"> • Be treated as a competent human being. 	<ul style="list-style-type: none"> • Be honest with the agencies you deal with.
<ul style="list-style-type: none"> • Ask for what you want. 	<ul style="list-style-type: none"> • Be flexible enough to look for alternative solutions.
<ul style="list-style-type: none"> • Expect confidentiality. 	<ul style="list-style-type: none"> • Ask what will be done with any information you provide.
<ul style="list-style-type: none"> • Take notes. 	<ul style="list-style-type: none"> • Inform the person you are speaking to that you are taking notes.
<ul style="list-style-type: none"> • Speak to someone who has authority to make decisions. 	<ul style="list-style-type: none"> • Request to see a supervisor if you wish to do so.
<ul style="list-style-type: none"> • Be free from discrimination based on race, colour, ancestry, place of origin, political belief, religion, marital status, physical or mental disability, sex, age or sexual orientation. 	<ul style="list-style-type: none"> • Be aware that government policy, regulations and funding priorities may get in the way to getting what you want.

Keeping records

Why keep records?

Keeping detailed and accurate records is absolutely essential to the advocacy process, even though it seems like a chore sometimes. *Everyone's* memory is unreliable. When someone asks - "what happened" - you need to be able to tell him or her and back it up with facts as much as possible. When there are disagreements, you will make a stronger case if you have written down what happened.

What should you keep records about?

Conversations	Actions
<ul style="list-style-type: none"> • Who did you talk to? What was their name and position? Keep a separate record of <i>each</i> conversation <input type="checkbox"/> What was said? <input type="checkbox"/> When did the conversations take place? <input type="checkbox"/> Did you contact the person by phone or in person? 	<ul style="list-style-type: none"> • What action did they say they would take? • What action did you say you would take? • When and how will you know these actions have taken place? • Do you need to call back to follow-up?

What if you can't, or prefer to not to, take notes by hand?

You could:

<ul style="list-style-type: none"> <input type="checkbox"/> Use a tape recorder <input type="checkbox"/> Ask someone to make notes 	<p>People may be uncomfortable with the idea that the conversation is being taped. Be sure to tell them that you are using a tape recorder, and explain why.</p>
--	--

What kinds of information do you need to collect?

<ul style="list-style-type: none">• Your own notes	<ul style="list-style-type: none">• Letters that were sent to you. If anyone wants copies of these letters give them a photocopy. Keep the original.
<ul style="list-style-type: none">• Copies of letters you sent to other people	<ul style="list-style-type: none">• Information about laws and policies that apply to your situation.
<ul style="list-style-type: none">• If someone is helping you with your situation, you may need to provide written permission before agencies or organizations will talk to him or her. Keep a copy for your files.	<ul style="list-style-type: none">• Any other information that may help you make a case on your own behalf.

If people want copies of the information you have collected, and if you want to give it to them, ask them to make copies in their office. That way you won't have to pay for photocopying.

What are some ways to keep all the information you collect in one place? You could use:

<ul style="list-style-type: none">• an old envelope	<ul style="list-style-type: none">• a cardboard box
<ul style="list-style-type: none">• a three ring binder	<ul style="list-style-type: none">• a filing cabinet
<ul style="list-style-type: none">• a file folder	<ul style="list-style-type: none">• anything that works for you

Communication Tips

There are a number of ways to approach people about your situation. No matter which method you choose, the ability to make yourself heard and to listen to what other people are saying will increase the chances of getting what you want. No matter how upset you are or how badly you feel you have been treated, there are a few things to keep in mind:

Take responsibility for your own feelings

You have the right to be safe from physical and verbal abuse and so does the person you are talking to. If you direct your anger at them, it can make the person you are talking to uncomfortable, and communication will stop.

Try these suggestions:

- Before you pick up a phone, or put anything on paper find someone you trust to be your coach.
- Choose someone who can help you stay calm and who can give you support if you are feeling angry or upset.
- Try to anticipate the kinds of questions you might be asked.
- what is likely to trigger your anger or make you feel upset?
- Practice discussing these topics with your coach.
- You could ask your coach to go with you to the appointment, be in the room when you make the phone call, or read a letter before you send it.
- If you do feel angry or upset while you are advocating take a deep breath, calm down, and keep on going.
- You may not do it perfectly, but you'll know you tried.

Give credit where credit is due.

Sometimes people in agencies or organizations are helpful or work hard on your behalf even though, in the end, they may not be able to help you get what you want. Let these people know you appreciate their efforts. You are building relationships for the future.

Be assertive, not aggressive.

You are being *assertive* when you:

- Use a 'reasonable' tone of voice/attitude.
- Are brief, clear and consistent.
- Keep asking for explanations until you understand what is being said.
- Listen to what the other person has to say and repeat it to show that you understand. You don't have to agree with them, but try to understand that they may have a different point of view.
- Make sure the other person understands what you said. They don't have to agree with you, but make sure they know *your* point of view.

You are being *aggressive* when you:

- Shout or yell.
- Make physical or verbal threats.
- Don't let the other person talk.
- Constantly interrupt.
- Make no attempt to understand the other person's point of view.
- Withdraw from the discussion.

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Worksheet #1 What happened?

You will probably be asked to tell and re-tell your story many times. This may require some preparation and a lot of patience on your part. It will be helpful if you can be brief and consistent as you describe what happened.

Your situation could be fairly simple or very complex. The questions on this worksheet are intended to help you be clear about the details. If you have been collecting information and keeping records as you go along, that information will be helpful in filling out the worksheet now.

What did you ask for that you didn't get?

When did the situation happen? (time, date, place, etc.)

Whom did you talk to? (name, position, location of office)

**What reasons were used for not giving you what you asked for?
Was the refusal based on a particular law or policy?
What was it? Be exact.**

What will happen if this situation isn't resolved right away?

What do you want to happen in this situation?

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Worksheet #2 Looking for Alternatives

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Before you can make a case for getting what you asked for, you may need to show that you have looked at other ways to solve your difficulties. One way to do this is to find out what people in similar situations have done.

In some communities, women's centres, service clubs, church groups and others may offer food, furniture, information, referrals and support. Your community might have a brochure listing free and low cost services, or you could check with a community resources agency. If you feel comfortable doing so, ask your friends and neighbours what they have done in similar circumstances.

Are there other ways to find what you're asking for? Can you get this particular thing or service somewhere else? Could you make do with something else? Is there some other approach that would be satisfactory? Write down all the alternatives you can think of.

Is there an administrative review or appeal process? is there a complaint line? Who would know?

What does the agency/organization you consulted say about your chances for success in this situation?

Would it be worthwhile to get another opinion? Yes No

Maybe some other agency or organization has had more success in resolving your particular issue. Check it out. Advocacy requires persistence.

Try contacting the government Ministry or Department which funds the agency where you are advocating. Will your local MLA or MP intercede on your behalf? Is there a licensing board or review board? What did you find out?

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Worksheet #4 Advocacy in person or by phone

By this time, you're clear about what happened, you've looked at alternative solutions to your difficulties and have kept records to show how you've tried to resolve the problem. You know why your original request was refused and you've checked out what your rights are. You know what you want to happen in this situation. You know which laws and policies support your request. You are now ready to go ahead and present your case.

Before you do that, it might be useful to go over the following check-list.

CHECKLIST	NOTES
What is the name, phone number, title of a person who has the power to make a decision in your situation?	
Can you talk to this person on the phone, or do you need to make an appointment?	
If he or she is not there when you call, what is a good time to call back? What is a good time for him or her to call you back?	
If you are going to advocate in person, what do you need to know about the physical location of the agency? <ul style="list-style-type: none"> <input type="checkbox"/> the address of the office <input type="checkbox"/> is it accessible to you? <input type="checkbox"/> where can you park? <input type="checkbox"/> is there a bus stop nearby? <input type="checkbox"/> what bus will get you there? 	

CHECKLIST (continued)	NOTES
<p>Do you need to have any of the following information ready before you begin?</p> <ul style="list-style-type: none"> <input type="checkbox"/> file or client number <input type="checkbox"/> social insurance number <input type="checkbox"/> photo i.d. <input type="checkbox"/> birth certificate(s) <input type="checkbox"/> immigration papers <input type="checkbox"/> receipts <input type="checkbox"/> letters from doctors or other professionals <p>What documents specific to your situation do you need to have ready?</p> <ul style="list-style-type: none"> <input type="checkbox"/> _____ <input type="checkbox"/> _____ 	
<p>What do you want to happen in this situation?</p>	
<p>You have the right to take someone with you to an appointment as an advocate, as a witness, as a translator, or to give you support. Do you want someone to go with you? Who?</p>	

A Reminder

Keep a record of each conversation you have.

When did you call?

Whom did you talk to?

What did *they* say?

What did *you* say?

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Worksheet #5 Advocacy by letter

Instead of personal or phone contact, you may wish to write a letter. There is a sample letter on page 19.

Some guidelines for writing an advocacy letter:

- Keep it short (not more than one or two pages).
- Be courteous.
- Make sure the letter is readable.
- Write about only one issue per letter.
- Try sending your letter by fax or e-mail. E-mail yourself a copy, too.

What to include in an advocacy letter:

- date
- your address, including postal code
- name of person you are writing to
- name of agency/government department
- their address, including postal code
- salutation: Dear _____
- a statement of what you want from the person you are writing to
- a brief description of the situation
- the names of people you have already contacted to try and resolve the situation
- evidence to support your position, if appropriate
- a statement of what you want to happen in this situation
- a closing statement
- your name
- a telephone number or address where you can be reached or a message can be left.

Sample advocacy letter

April 25, 1997

1234 High Street
Penticton, B.C.
V2AOHO

Helen R. Supervisor
Ministry of Bureaucratic Entanglements
Parliament Buildings
Victoria, B.C.
V2R4X8

Dear Ms. Supervisor:

Your office says I did not send proper receipts in order to get reimbursed for some health expenses. I would like you to help me sort this out.

Here is what happened. On February 14, I called the Penticton office and spoke to Chris who said that in order to get reimbursed, all I needed to do was send in Form A with the receipts. I sent them on March 17. J. P. Folks from your office called on March 21 saying that I also needed to submit Form B.

I sent in Form B on March 22. I got a letter dated April 1 from your office saying that I had never sent in Form A. I called your office on April 2 and talked to Kim to say that I had already sent in Form A along with the receipts and that Jody had called me about Form B. Kim insisted that they had not received Form A or the receipts. When I suggested that she ask Jody, Kim said that Jody no longer worked there. I pointed out that the office must have received Form A or I wouldn't have known to send in form B.

I didn't keep a copy of the receipts I originally sent in. Your office has lost them. Would you please look into this and call me at 490-0000 by April 30 to let me know when I will be reimbursed for my health expenses.

I am feeling very frustrated by this situation and I would appreciate your help in getting it resolved.

Thank you,

S. Smith
Card number: A012345B67C

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Worksheet #6 What next?

You have just been through a very thorough advocacy process. Give yourself a pat on the back for your hard work and persistence. However, after all that effort, you may not have been able to get what you wanted. This worksheet can help you evaluate what your options are from this point.

Appealing the Decision

From the research you did earlier, you know if there is an appeal or review process. You will need the following information before you decide whether to appeal:

If there is an appeal process...	Notes
Do you have to appeal within a certain period of time?	
Does the appeal have to be on the agency's forms?	
Where you can get appeal forms?	

If there is an appeal process...	Notes
Is there a supervisor or government department which handles complaints about this agency.	
Would it be better to go to a supervisor or manager before making a formal complaint?	
Where you can get appeal forms?	

You have done a lot of work to get this far. If you are not satisfied with the outcome, you may feel that it is too much effort to keep on going. You may have some other issue to deal with now, or you may want to take a break. Whatever you choose, you can be confident that the next time you go through this process you will be well prepared. You already know how to advocate for yourself

Support and advocacy groups

Sometimes, no matter how hard you work or how well prepared you are, you won't be able to find a way around a law or policy that is keeping you from getting what you want. Other people have probably experienced the same kinds of difficulties. Check out resources both locally and provincially to see if there is a group that you can join with to work for change at the political, legal, or economic level.

What do you want to do now? Review the following options?

You could:	Advantages?	Disadvantages?
Appeal.		
Let it go.		
Take your case to a support or advocacy group.		
Consider other options.		

Questions and Answers

Q. What if the person I want to speak to isn't available or won't answer my calls?

A. Ask when the person you are trying to contact will be in his or her office. Arrange to call back then. If you say you are going to call at a specific time, make sure you do. Or you could arrange a time for the person to call you back. If the person does not call, or seems to be avoiding you, ask for the name and phone number of the supervisor and let him or her know about the situation.

Q. What if the person I need to speak to uses a lot of technical terms or jargon and I don't understand what they are saying?

A. You have the right to be spoken to in a way that you can understand. However, if you don't understand what is being said, or if it is not clear to you, you have a responsibility to ask the person to use other words.

Q. What if the person I have to deal with makes me feel inferior or as if they are doing me a big favour?

A. If it is a service-providing agency, you have the right to ask for service. Services wouldn't exist without people to use them. Remember that every person has equal worth and value, no matter what side of a desk he or she is sitting on.

Q. What if I suspect that I am being discriminated against because of my race, colour, ancestry, place of origin, political beliefs, religion, marital status, physical or mental disability, sex, age, or sexual orientation.

A. You may be able to deal with the matter directly at the agency level by letting the supervisors and managers know about your concerns. However, you may also wish to check with the Human Rights Branch to see if a formal complaint is appropriate.

Q. What if I am afraid to ask for what I want because standing up for myself might make the situation worse?

A. Sometimes individuals are concerned about asking for what they want. They may fear that people who have power to make decisions might become angry and take it out on them, or someone close to them. Here are some suggestions about how to deal with fears about *retribution* or *retaliation*, as this kind of behaviour is sometimes called.

- Bring your concerns out in the open.
- Try to begin the discussion about your fear of retaliation in a positive way as a concern that needs to be addressed, not as an accusation against the person or organization you are talking to.
- Discuss what kinds of behaviours and actions would feel like retaliation to you; for example, unnecessarily holding back a cheque, withholding services, or mistreating a vulnerable family member who is not able to speak out for him or herself.
- Before you leave, go over what was discussed so that you know that you and the person you are talking to have the same understanding about what will happen in this situation. Be sure to keep your own notes.
- Thank the person you are talking to for understanding why you need to bring this matter up.
- Give yourself a pat on the back for having had the courage to talk about a very difficult subject.

This answer has been adapted with permission from materials prepared by
Cathy Bedard and Janet Phillips
of the BC Coalition of Parent Advisory Committees.

'The AdvoKit':

A step-by-step guide to effective advocacy

- Step 1: Be clear about what happened.**
- Step 2: Look for alternative solutions.**
- Step 3: Prepare your case.**
- Step 4: Talk to the right people**
- Step 5: Evaluate what worked and what didn't.**
- Step 6: Decide what to do next.**

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To:

4 Phases to the Advocacy Process

1. PREPARE

Define the issue

- list the issues
- identify the key issue

Gather information from

- community organizations
- services & resources
- past advocacy efforts

Identify supporters

- consumers
- decision-makers
- public

2. PLAN

Review the issue & identify the preferred solutions Choose the route

- take stock of resources
- identify all possible systems
- select most appropriate system

Develop the action plan

- assign tasks
- review & revise the plan where necessary

3. ACT

The **ACT** phase involves carrying out the action steps systematically

4. EVALUATE

The **EVALUATE** phase reviews the changes that occurred, taking into account the process & its effectiveness.

This phase sets the stage for future action

Worksheet #1

Phase 1: Prepare Define the Key Issues

1. Issues

2. Key Issue

3. Who is affected by this issue?

4. How are these people affected?

5. The priority of this issue is:

low___ medium___ high___ don't know___

Worksheet #4

Phase 4: Evaluate Effectiveness of Action Plan

1. What strategies worked? Why?

2. What strategies didn't work? Why?

3. Were resources adequate? Why or Why not?

4. Were the appropriate people involved?

5. Was the desired result achieved?

6. What could improve the plan?

An Effective Advocate is...

- **Focused**
It is unrealistic to believe that you can make everything better for everyone...
Select something you feel passionately about & stick with it.
- **Informed**
Learn as much as you can about the issue.
Know your rights & find out who the key players are.
- **Articulate**
Develop your public speaking & letter writing skills.
- **Assertive**
Speak up for your rights...
firmly & confidently
- **A Good Listener**
Seek first to understand & then to be understood.
Ask questions to ensure that you fully understand the message you are receiving.
Give your full attention to the speaker & do not interrupt.
- **Committed**
It is important that you feel passionately about the issue in order to have the resolve to hang in there when things don't go as smoothly as you would hope.
- **Perseverance**
It takes a great deal of energy to keep going when you run into road blocks.
- **Self-Confident**
Be prepared to take risks and
Expect success!

Tools for Personal Organization When Problem Solving an Issue

1. Calendar

Buy a calendar with large squares for writing important family information on such as: appointments, interviews, games, practices, parties, special occasions, PROMISES. Keep the calendar up on the wall so the whole family can check it out at the beginning of each week and everyday, if necessary.

2. Appointment Book

Keep an Appointment book (the Month at a Glance type) and keep it with you at all times. Then you won't forget to follow up on appointments, invitations, interviews, etc. and people will be incredibly impressed with your organizational skills.

BUT... When you get home you must put any new information on the big calendar. Every member of the family does this. Children can use school planners, which are always in their backpacks. Set a regular time for matching the calendar with the appointment books.

3. Message Center

Set up a message center near your phone so that messages can be received and recorded accurately. Suggestions for your center: A container full of sharp pencils and working pens, a small box with re-cycled paper cut in sizes big enough for one message only, answering machine and telephone (one that can't be walked away with), a designated place for written messages (boxes for each person, bulletin board, etc.)

4. File

File any item, original or copy that has to do with an issue, problem, project, child's diagnosis, etc.

Items like:

- Doctor's letter of diagnosis, or written and signed statement that there was no disability found.
- School or district assessments or written and signed statements that there was no disability found.
- Teacher's statement of accommodations provided for your child.
- Children's services assessments
- Interim and final report cards
- Individual Education Plans

- School, School district and Ministry policies
- Letters received or copies of letters written by you
- Receipts showing payment for services or equipment that were used to deal with an issue. (You may find that your family or child qualifies for a program that helps pay for support for those with disabilities).
- Notes you took at school conferences, school board meetings, professionals' visits, etc. Include date and the time of day.

The file can be as simple as an old or used large envelope with the general idea of the subject written on the outside in black pen or as complete as a file cabinet and file folders. The files can be inside a cabinet drawer, cardboard box or whatever you choose. The important thing is to keep these items in a systematic way for many years so they can be retrieved if necessary.

5. Policies

Keep copies of policies that apply to a situation you are dealing with and the process for putting the policies into practice. You use these policies to verify that the employees have or have not followed Policy and Process.

If you find you need to go further with an issue, you then:

- Phone the main number of the agency or department that is responsible for enacting that policy and ask to speak to the person who looks after the issue.
- Write the name of everyone you talk to and what their position is, even the receptionist.
- Ask what their protocol is for you to follow. (Use their names in the conversation).
- Write down information you are given and ask them to repeat what they say. This establishes that you are serious and will quote them if necessary.
- Put down the day and time of the contact even if they are supposed to call you back. Make a note of the expected time, too. Later, make a note if you did not get a returned call.
- Put all of this in a file until you are finished with the issue. Keep these files for a long time. There may be an incident or parent-action at a much later time where your records could be very important. This may be especially important if you have younger children coming up through the same school system.

You may find it helpful to write the department, the employee(s), and their office staff(s) names and telephone numbers in your phone index for future use.

6. Phone Index

Organizing all phone numbers means you can get to the people you want as soon as action is required. Not having a zillion pieces of loose paper with numbers and no names keeps you sane! This may be part of your appointment for ready reference.

7. School Handbook

Your school handbook, can be a binder which includes school and district policies such as:

- Absenteeism and tardiness
- Code of Conduct and the consequences for not following it
- process for appealing a decision to the school board (any administrative decision can be appealed)
- process for the failure of a school board employee to make a decision that significantly affects the education, health, or safety of a student, etc.

8. Notebook

Keep a blank notebook for recording the important who-said-what-where-when and why. Take it to every school meeting, Parent council, parent-teacher interview, every appointment relating to an issue, to municipal meetings, etc. Being able to accurately restate what was said in your presence is a positive empowering act. This also cuts down on people gossiping and passing on inaccurate information.

9. Your Network

Keep track of your support network, other parents, friends, neighbours, professional supports, all the people you can call on to share information and develop strategy with. Be prepared to support them in return for their support of you. Perhaps keep a special list in your appointment book for handy reference or keep a file.

10. The Letter

Letters can be very powerful for your purposes so do the job right.

- a) Personalize your letter. Use "me, my family, our child in elementary school, our neighbourhood". Then how this issue or problem affects our family. This ensures you will get a personal reply. Imagine the work required when seventy people send personalized letters to the same official!! If you send a form letter, you will receive a form letter.
- b) Specify the NEED your child has. "My son needs a room to work in where there are no distractions." "Due to my daughter's short-term memory deficit, she needs her homework assignments written in a planner, log book, or home-school communicator."
- c) Encourage school-based support letters. Give all the parents in the school a one-page handout outlining the issue, how it affects the school, the students, etc. and some ideas for them to write something from their perspective about the issue.
- d) Take picture, or even videos of the problem. Accompany with this useful quote, "Classroom is a home. It is not feasible to cut programs for some of the family. The family is a whole."

- e) Copy the letters and keep the copies in your files. Send copies to people who have or should have some interest or responsibility for this issue. When you send copies, always put cc: and the name and job title of the person you send the copy to at the bottom. It helps to write a short cover letter explaining why you are sending the copy to the recipient. Sending copies shows your commitment to the issue and alerts the other recipients to the hard fact that this becomes everybody's issue.
- f) Use your own handwriting, if it is clear enough to read. This shows the recipient that you are not dictating to an employee.

11. Additional Helpful Hints

- a) Phone calls are most useful when you call as soon as the office, school, agency is open for the day. Call early in the week. Ask when you can expect a return call if the person you want is not in.
- b) Get copies of Acts, Policies, Regulations; drafts of Proposed Documents, Rights of People with Disabilities. Most agencies and offices are willing to send you these free of charge or will ask you for the cost of copying.
- c) Non-Profit Agencies exist to provide services. Use them.
- d) Know and use correct respectful language for people with disabilities. Put the child or person first, then their label, if necessary. (A person with a disability, a child with autism, etc.)
- e) Be assertive. If necessary, take an assertiveness workshop. Take a book out of the library on assertiveness training. Observe others who get what they need, or want.
- f) Act on issues as they arise, if you leave a problem too long, your impact is weakened.

RRP Orientation/Advocacy

Additional Materials/Session #2/orientation Sessions/RRP Committee

Documentation

Documentation can be as simple as keeping notes for your own records or, it can be as formal as writing a letter to the premier.

Keeping written records of conversations, meetings or other correspondence provides a means for keeping everyone accountable.

It is important that you document when:

- You are requesting services
- You are dissatisfied with a service
- You are requesting a meeting with administrators, government or other officials
- You are lobbying for the development of new services
- You want to file a complaint
- You are setting a deadline for action

It is important to request documentation when someone is:

- Making a promise to provide a service
- Delaying access to services due to waiting lists
- Denying access to services for any reason
- Requesting to meet with you
- Referring you to another person or service
- Providing information
- Responding to your complaint, request or appeal

Taking Notes:

- Take notes of telephone conversations:
 - remember to record the name, title, department & phone number of the person you have spoken to
 - record any promises made
 - note any dates
 - summarize the conversation & seek clarification for anything you don't understand
- Keep a file of all correspondence pertaining to the issue or problem
- Take notes at every meeting you attend (or take someone with you who can do this for you)

When writing letters:

- Be brief
- Be courteous
- Write about only one issue per letter
- Make sure the letter is readable
- State the problem clearly, and objectively
- State what you expect them to do, by when & why
- Refer to policies, regulations or legislation
- Request a written reply, stating your intentions if they do not comply
- cc the letter to others as appropriate
- Keep a copy for your files
- Follow up letters with phone calls & phone calls with letters

Be sure to include:

- Date
- Telephone number where you can be reached
- Your address, including postal code
- Name of person you are writing to
- Name of agency or department
- Their address, including postal code

Date

To: Recipient's name & title
Recipient's address

From: Your name
Your address
Your phone number

Dear _____ ,

My name is _____. I am the parent of _____ (*include a description of your child; age, "diagnosis", etc.*)

I am concerned about _____ (*explain what is happening, how long it has been going on, who is involved and anything that has been done to try to solve the problem*).

I would like to suggest _____ (*include your ideas about how to resolve the issue*).

I would like to meet with you to discuss my concerns. (*If you want to take a support person with you, you could add the next sentence.*) I would like _____ (*person's name*), who is my (*or, my son's/daughter's*) _____ (*support person, social worker, behavioural consultant*), to join us for the meeting. Please contact me as soon as possible.

Thank you for your prompt attention to this matter.

Sincerely,

General Tips for the Meeting:

- Ask questions.
- Voice your opinion.
- Focus on the issues, not the people.
- Seek facts.
- Use good communication skills.
- Take careful notes or have someone else take them for you.
- Make sure that information presented by professionals is clear and understood by you.
- If financial concerns are expressed, be supportive but do not back down on your request or accept responsibility for the problem.
- If you need to be confrontational it should be a strategy, not a result of anger.
- Know your bottom line, where you will trade off and where you won't. Ask yourself, "Can I live with this decision?"
- Summarize the discussion and review the decisions made.
- Do not agree to decisions or sign anything you are not ready to. (It is all right to say that you need time to think about it or discuss it with your partner.)
- If someone else has taken minutes, ask for a copy.
- Set follow-up meetings if necessary.
- Know the next steps.

Meetings

Meetings may be called to resolve an issue, acquire information, or to plan for your child's future.

Meetings may be called by parents, teachers, social workers, or other professionals.

It is important to be well prepared for meetings. The following information is intended to help you to be better prepared for meetings.

Pre-Meeting Preparation:

- Be clear on the purpose of the meeting, regardless of who has called it. Know if any decisions are to be made at the meeting. Consider preparing or asking for an agenda.
- Prepare your own presentation. Keep it brief and focused. Be realistic about what can be covered in one meeting. Decide what materials to bring.
- Know who will be attending and what their role and degree of involvement with your child is.
- Invite your own support persons, therapists, etc. and notify the person who called the meeting of their attendance. Make copies of materials for them on anything you may be presenting and let them know what your position is.
- If possible, both parents should attend meetings. This may mean that people will have to meet at a time that enables working parents to attend.
- Find examples of what you want for your child. For instance, if you are presenting a case to the school board, they may find it easier to understand if you present an example of what you want.

Following the Meeting:

- Give yourself some time for reflection after the meeting. Check how you are feeling. Have some feelings surfaced that you were unaware of at the meeting? If so, take note of them.
- Check out your perceptions and feelings with your support person.
- review your minutes and add anything you missed.
- Compare your minutes with minutes of others you have received.
- Are you satisfied with the process of the meeting, the results, the solutions and the strategies? Did you feel listened to and did you listen to them? Is there anything you could do better? Is there anything they could do better?
- Was a follow-up meeting set?
- Are you clear what will happen next or where you are going?
- Respond in writing to the person who chaired the meeting outlining your understanding of major points covered, decisions made, and indicate whether or not you are in agreement.
- Note dates set for accomplishment of tasks (if any), your future role or responsibilities if designated, and include your positive feedback.

UNIVERSAL DECLARATION OF HUMAN RIGHTS

UNITED NATIONS HIGH COMMISSIONER FOR HUMAN RIGHTS

Source: United Nations Department of Public Information <http://www.unhchr.ch/udhr/lang/eng.htm>

Usage by Country

Europe –
Official Language: UK,
Gibraltar, Ireland, Malta

Asia –
Official Language: India,
Pakistan, Philippines,
Singapore

Africa –
Official Language:
Botswana, Cameroon, Gambia,
Ghana, Kenya, Lesotho,
Liberia, Malawi, Mauritius,
Namibia, Nigeria, Sierra Leone,
south Africa, Swaziland,
Tanzania, Uganda, Zambia

Central and South America –
Official Language:
Anguilla, Antigua & Barbuda,
Bahamas, Barbados, Belize,
Bermuda, Br. Virgin Isl.s,
Dominica, Falklands, Grenada,
Guyana, Jamaica, Montserrat,
Puerto Rico, St. Kitts & Nevis,
St. Lucia, St. Vincent, Trinidad &
Tobago, Turks & Caicos
Islands, US Virgin Islands

North America –
Official Language: USA,
Canada

Oceania –
Official Language:
American Samoa, Australia,
Belau, Cook Islands, Fiji,
Guam, Kiribati, Marshall
Islands, Micronesia, Nauru,
New Zealand, Niue, Norfolk
Islands, Northern Mariannas,
Papua New Guinea, Solomon
Islands, Tokelau, Tonga,
Tuvalu, Vanuatu, Western
Samoa.

Universal Declaration of Human Rights

Preamble

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,

Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in Cooperation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, therefore,

The General Assembly,

Proclaims this Universal Declaration of Human Rights as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration Constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

History

It belongs to the Indo-European family, Germanic group, West Germanic subgroup and is the official language of over 1.7 billion people. Home speakers are over 330 million. As regards the evolution of the English language, three main phases can be distinguished. From the 6th and 5th centuries B.C., the Celts are believed to have lived in the place where we now call Britain. Britain first appeared in the historical records as Julius Caesar campaigned there in 55-54 B.C. Britain was conquered in 43 A.D. and remained under the Roman occupation until 410 A.D. Then came from the European Continent the Germanic tribes, who spoke the languages belonging to the West Germanic branch of the Indo-European language family. First the Jutes from Jutland (present-day Denmark) in the 3rd century A.D., then in the 5th century, the Saxons from Friesland, Frisian Islands and north-west Germany, finally the Angles, from present-day Schleswig-Holstein (a German Land) who settled north of the Thames. The words "England" and "English", come from the word, "Angles". During the Old English period of 450-1,100 AD. (first phase), Britain experienced the spread of Christianity, and, from the 8th century, the invasion and occupation by the Vikings, called the "Danes." The most important event of the second phase, the Middle English period (1100-1500 A.D.) was the Norman Conquest of 1066.

Article 1

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 2

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

Article 3

Everyone has the right to life, liberty and Security of person.

Article 4

No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

Article 5

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

Article 6

Everyone has the right to recognition everywhere as a person before the law.

Article 7

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 8

Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

Article 9

No one shall be subjected to arbitrary arrest, detention or exile.

During the third phase, the Normans were the North Men, meaning the Vikings from Scandinavia, settled in the Normandy region of France from the 9th century, who had assimilated themselves to the French language and culture. English was much influenced by French during this time. Modern English period (1500 onwards), English spread to the world as the British Empire colonized many lands. William Shakespeare (1564-1616) lived in this period, and in 1755 Samuel Johnson completed "A Dictionary of the English Language" with about 40,000 entries, which contributed to the standardization of the English language. The English language, which spread to the world created many of its variants, the most prominent of which is American English. The American English writing system is said to owe much to Noah Webster's "An American Dictionary of the English Language" which was completed in 1828. Other important varieties include Indian English, Australian English, and many English-based Creoles and Pidgins.

Article 10

Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations and of any criminal charge against him.

Article 11

1. Everyone Charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial at which he has had all the guarantees necessary for his defence.
2. No one shall be held guilty of any penal offence on account of any act or omission which did not constitute a penal offence, under national or international law, at the time when it was Committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the penal offence was committed.

Article 12

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Article 13

1. Everyone has the right to freedom of movement and residence within the borders of each State.
2. Everyone has the right to leave any Country, including his own, and to return to his country.

Article 14

1. Everyone has the right to seek and to enjoy in other countries asylum from persecution.
2. This right may not be invoked in the case of prosecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

Article 15

1. Everyone has the right to a nationality.
2. No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality.

Article 16

1. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
2. Marriage shall be entered into only with the free and full consent of the intending spouses.
3. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

Article 17

1. Everyone has the right to own property alone as well as in association with others.
2. No one shall be arbitrarily deprived of his property.

Article 18

Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

Article 19

Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 20

1. Everyone has the right to freedom of peaceful assembly and association,
2. No one may be compelled to belong to an association.

Article 21

1. Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.
2. Everyone has the right to equal access to public service in his country.
3. The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

Article 22

Everyone, as a member of Society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 23

1. Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.
2. Everyone, without any discrimination, has the right to equal pay for equal work.
3. Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.
4. Everyone has the right to form and to join trade unions for the protection of his interests.

Article 24

Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

Article 25

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.
2. Motherhood and childhood are entitled to special care and assistance. All children whether born in or out of wedlock, shall enjoy the same social protection.

Article 26

1. Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.
2. Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.
3. Parents have a prior right to choose the kind of education that shall be given to their children.

Article 27

1. Everyone has the right freely to participate in the Cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.
2. Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

Article 28

Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

Article 29

1. Everyone has duties to the community in which alone the free and full development of his personality is possible.
2. In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.
3. These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

Article 30

Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

Working With the Professionals In My Child's Life

Sometimes I feel overwhelmed. "How can I evaluate every person or service? How do I know which is best?" Then, I remember that it's a team approach. I'm not alone. It's just my job to get the specialists I trust to talk to each other. I remind myself that they know their work and I know my child.

– MELD Special Parent

A resource team is like a net that supports and nurtures a child with special needs. Parents are the most important strands in that net, but it is difficult to support our children all by ourselves. A team of professionals, friends and others are needed in order to help children develop to their full potential. Together, the team members can make a net that adequately supports the child.

A team approach to caring for children with special needs has many benefits.

- Children benefit when they receive services from a team of people who are working together and being good role models. Children who are supported by a helpful team approach learn they can participate in decisions about their care. They tend to have higher self-esteem and learn self-advocacy skills more quickly than do children who receive care from fewer cooperating adults.
- Parents benefit from not having to provide all the services ourselves and can relax a little knowing others are also able to support our children. A good team approach helps maintain our legitimate partnership role with professionals so our decision-making and parental power don't get taken over by others. As we become comfortable with our team we may find ourselves growing personally and our belief in our competence increases. We gain in overall sense of how systems work and we can find other assistance more easily when our children need it.
- Friends and informal support people benefit from being included on the team. Too often their value is not acknowledged or they are not asked to provide assistance when often they are able and willing. Our supportive friends will better understand how much we value them when we take their roles seriously, include them in discussions about our children's needs and verbally recognize their support.

For Parents Who Have Children With Special Needs

This is a **SAMPLE** brochure from MELD "Hands on Help for Parents"

MELD
123 North Third Street, Suite 507
Minneapolis, MN 55401
Phone: 612-332-7563 VITTY
Fax: 612-344-1959

- Professionals often benefit when there is a team. They are given more complete information because it comes from a variety of sources on the team. They can better plan and provide services when they know of the other support in place for our children. Professionals can trust that treatment plans will be carried out if all the people involved with that service have agreed to it. Professionals who are working as part of a team can act more human; they don't need to be all-knowing and solely responsible.

There are many things that we, as parents, can do to foster teamwork with professionals so that they become allies in serving our children. We can:

- Develop positive communication skills by using assertive language and good listening techniques.
- Choose professionals who "speak parent-friendly language".
- Be prepared for meetings. Write any questions down ahead of time. Draw up an agenda so everyone is on the same page.
- Share what we know about our children with the professionals. Tell them about our children's world, family, likes and dislikes, strengths, etc.
- Deal with one topic at a time. Speak up in a non-aggressive manner. Ask questions, voice concerns, share our ideas.
- Say "no" to unwanted programs or support. Take a break from services when feeling overloaded.
- Be a partner to the professionals, recognizing they are only human, too. Understand their bad days and acknowledge their "good" days. Let them know they are appreciated.

SAMPLE Brochure from MELD