

New Resource Parent / Resource Family Member Orientation Manual



**FAMILY SUPPORT
INSTITUTE of BC**

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****Please note: Throughout the booklet RP will refer to Resource Parent (RP)/ Resource Family Member (RFM)**



I. Who Is Family Support Institute of BC?

The Family Support Institute (FSI) is a provincial non-profit charitable society registered in 1985. FSI supports approximately 10,000 families who have a family member with a disability each year. This support stems mainly from our large volunteer network of Resource Parents (RP's). Currently, FSI maintains a RP Network of over 200 volunteers who support families across the province by sharing experiences and expertise, connecting families with each other, guiding families to supports and services and community supports in their regions, and facilitating training and educational sessions including building capacity in the areas of innovation and creative solutions. FSI's supports and services are free to any family. FSI is unique in Canada and is the only grass roots, parent-to-parent support organization with a broad volunteer base. FSI is not an advocacy organization. FSI believes that families are ultimately the strongest voice, when it comes to their children. We support all families, with children of all ages and all disabilities including mental health challenges.

Our Vision

All individuals and families are supported, connected and fully valued in their communities.

Our Mission

To strengthen, connect and build communities and resources with families of people with disabilities in BC.

Belief Statement: We honour that the Family Support Institute grew out of an era that did not value the pivotal role of families. Therefore, we believe:

- That families are the best voice to speak for their own unique circumstances.
- Families have a critical role in shaping the future for their family members.
- Families are the best resource to support one and other.
- Informed families are more empowered to speak for themselves when needed.
- Informed, involved, confident families are the most effective agents for creating social change.

What We Do:

- Listen to families' and support them through their concerns and struggles, and requests for information.
- Offer families a new way to look at their situation.
- Support and encourage families to reach out, ask for what they need, and build positive, supportive relationships.
- Show families where they can acquire new skills to help address their issues.
- Increase awareness of FSI by continuously educating and spreading the word of who FSI is to families, schools, government and professionals.
- We assist schools, government and professionals better understand the 'parent/family member perspective'.



How We Do It:

- Link families with other families and appropriate supports.
- Direct parents/family members and professionals to resources in the community.
- Provide information to the public on issues relating to family members with a disability.
- Communicate with government ministries to ensure the needs of family members with disabilities are acknowledged.
- Sit on various committees, when requested, which are appropriate to advance the voice of parents/family members who have a family member with a disability.

What We Don't Do:

- Provide services such as respite or financial aid.
- Criticize or judge a family's situation, request, or actions.
- Encourage dependency.
- Advocacy

More on Advocacy:

Do we Advocate or don't we? Our answer is always the same – no, we do not. However, we DO coach, support and mentor families how to advocate for themselves. FSI will not do the advocacy for families, but we will support families to have their own voice heard. We are also careful to help families understand that, whenever possible, they are always better to be in relationship with people/organizations rather than in conflict. Their voices are how families directly influences systems. FSI's role in advocacy is supporting families to use the appropriate processes, appeals and systems in the right way, at the right time.



II. Family Support Institute of BC RP Description:

All FSI RPs are parents, guardians, or relative of an individual with a disability, and who have an active role and/or vested interest in the life of their loved one. Our volunteers have developed unique skills, acquired knowledge and gathered experience that they bring to the FSI network and share with families in similar situations to their own. This large network allows all FSI RPs to also support each other, be supported by the office staff and find connection and community at the annual training weekend.

The responsibilities of RP's are summarized within the following:

1. In your role as a RP you will be asked to:

- 1.1** Receive phone calls and emails from families looking for emotional and other support.
- 1.2** Perform community outreach to increase awareness of FSI by educating and spreading the word of who FSI is to families, schools, government and professionals.
- 1.3** Communicate well by listening to other families' ideas without passing judgement as well as share stories, experiences, and expertise.
- 1.4** Attend FSI's annual Training Weekend in an effort to stay connected with the larger network.

2. (Optional roles) With approval and guidance from the FSI office, you may also be asked to:

- 2.1** Supporting families in person and/or attend meetings with them (IEP's, medical appointments, ministry meetings, etc.)
- 2.2** Represent FSI at transition fairs or man FSI display table at events.
- 2.3** Be a workshop presenter.
- 2.4** Be a mentor to a new RP.

Important to Remember

Confidentiality

Confidentiality is of the utmost importance when supporting families and obtaining information about their circumstances or challenges. RPs are asked to ALWAYS respect an individual's or family's right to confidentiality. Should information need to be shared during the course of a support call, RPs are asked to follow the practice below:

- Only provide general information on a need to know basis.
- Only provide information to others when permission is obtained from the family.

Your Personal/Family Life Balance

The Family Support Institute recognizes that RPs have family obligations and will periodically find themselves too busy with their own lives, to support others. RPs can access the RP network at any time should they themselves require support as FSI encourages all RPs to maintain a healthy balance between self-care and supporting others.



1.1 Family Support Call

The FSI office receives calls from parents, family members and professionals asking for support for a number of different reasons. Some examples include families wanting to talk with others who have “been there”, who know the emotional upheaval they are going through and who can help lead them through the maze of service providers. Families are looking for someone who truly understands because they have lived experience of parenting or being a family member of a child/family member with a disability. **Referred families want someone to listen, information, or both.**

FSI commits to responding to all support calls within a timely manner. RPs will receive requests for support from the main office, from other RPs as well as from other agencies. As such, **all RPs are required to respond to the families they have agreed to support within 2 days. Should this not be possible, RPs must let the office know immediately so that someone else can follow up.**

Responding to Requests for Support

- Set aside enough time to respond in whatever way the parent/family member needs.
- Don't expect to know everything during the call. Ask another RP, the office or a mento for help when needed.
- Greeting/Identicication
 - “Hello XXX, My name is Nancy and I am a Resource Parent with the Family Support Institute of BC. Bob from the office has asked me to call you. I'm a parent (or sibling) of a child (or family member) with a disability (or name the disability). Is this a good time to talk?”
 - If not, establish a better time for you to call back.
- **Listen, listen, listen!** Get the story:
 - Ask the family to describe what is happening.
 - Ask who have they talked to.
 - Inquire about the processes have they been through.
 - Verify what has already been done.
 - Ask what their thoughts are on next steps.
 - Take notes.
- Families are sometimes nervous to tell their own stories. Encouraging them with open-ended questions can be helpful. (“How was that for you?”) Avoid the use of “Why”.
- Be sure to focus on how the person is feeling. Reassure them all feelings are normal.
- Share your own experiences if appropriate, but keep the focus on the family and their story.
- Brainstorm solutions together, capture ideas on paper and send back to the family in a follow up email.
- Determine how you can help (i.e., Provide emotional support? Help gather information? Give them informational suggestions? Attend a meeting with them? Share resources?)
- Offer assistance but ensure permissions are obtained beforehand when necessary. “I could make that phone call for you, if that is helpful. Does that feel okay to you?”
- End the conversation on a positive note or with words of encouragement.
- Contact the office to inform them that contact with the family has been made.

- **Follow-up** with the family to check in and see how things are going. Welcome them to do the same.
- Don't expect to know everything during the call, ask another RP or your mentor for help.
- Set aside enough time to respond in whatever way the parent/family member needs.
- Be prepared to meet the family in person.
- **Respect Confidentially.**
- **Never turn anyone away.** The FSI office can assist when RPs run into a situation they are unsure how to handle.

Important to Remember

Emotional Support

Allowing parents/family members to feel their emotions (anger, guilt, depression, etc.) and to talk about them is all part of natural growth. Trust in the parent/family members' ability to handle their feelings, to work through them and to find solutions to their problems. You are there to help support them in this process. Parents/family members sometimes feel safer sharing emotions with another parent/family member. Call the parent/family member as needed, when a parent/family member demonstrates strong emotional needs. **Empathize with the grief a parent/family member may be feeling, understand that they may be at a different level of acceptance or coping than you are.**

Remain Non-Judgmental

Never place judgement on parents/family members for different philosophical beliefs or different racial and ethnic backgrounds.

Encourage Independence

The RP role it to help parents/family members to feel in control and not dependent on the RP. Let them know you are there to help them examine alternatives and assist them in arriving at solutions, but allow them to decide whether to accept your help. Allow parents/family members to look at all options and examine different viewpoints before making a decision. The final goal should be independent and empowered parents/family members.

Sharing your own experiences is important, but keep in mind what worked for you may not work for others. Allow parents/family members their own mistakes. Even if you disagree with the direction parents/family members are taking, allow them to grow in the learning process.

Know What's Appropriate

- RPs should not try not to take on the role they are not qualified for. (Marriage counselor, child specialist, etc.) RPs are encouraged to refer parents/family members to more specialized help when necessary. Medical advice in particular should be left to doctors.
- RPs should not be afraid to say they don't know something. They are not expected to have all the answers. The role is more about a willingness to help the family find the answers or point the family in the direction where assistance can be obtained.
- Too much information can be overwhelming. RPs are asked to acknowledge this with families and to remind them to go at a pace that is comfortable for them.



Referring to another Resource

FSI is not a crisis center but we sometimes receive calls from families in need of support after they have exhausted all other avenues. If a person is in crisis, sometimes, it is best to meet the family in person, this can be reassuring to a family who is feeling isolated. Please listen and watch for any warning signs that the family may need additional support you may not have the skills to provide.

When it is necessary to refer a parent/family member you are supporting, to another resource, i.e. local association, community resource, etc., whenever possible call the resource yourself to find out if they can help this parent/family member and then connect the family.

As it is important for the FSI office to track RP activity, If you need to refer a family to another RP please

- contact the FSI head office to assist you with this
OR
- Inform the office if you have connected with the RP directly

If a parent/family member is in crisis, it is very hard for them to keep asking for help, and sometimes quite confusing to keep all the resources straight. Always ask the parent/family member if you can give his or her name and number to someone for a call back. Always be specific about who will be calling them and why. Follow up to be sure the contact was made and the information was helpful.

When a Parent/Family Member Needs More

Sometimes parents/family members need more than we are able to provide them. If you experience a situation where you feel that you are in over your head, be sure to call for help immediately or talk to the office for advice. It may be that the parent/family member's behavior is normal for their situation but you are not comfortable handling it or it may be that the parent/family member is showing signs of a serious condition. The following is a checklist to give you some idea of what is serious. **Remember these behaviors are serious if they take place repeatedly, not just a comment here or there.**

Warning signs:

- Being stuck or obsessed with an idea or emotion: unable to move on in life (i.e. Doctors are cruel, life is terrible, always angry or sad) with little or no forward movement.
- Lack of problem-solving skills; stuck on a purely emotional level; just "stressed out" or "burned out" all the time.
- Talk about giving up ("it seems hopeless", "useless", "what's the point").
- Talk about hurting others or hurting themselves; (these are cries for help, ask if they have a plan to do so).
- Strangely irrational (somewhat bizarre), off-the-wall comments, inability to concentrate.
- Failure to bond with or attach to the child/family member (lack of affection, speaks in negative terms, as if repulsed by the child/family member).
- Depression expresses itself in different ways with different people; lethargy; loss of zeal or interest in anything; loss of emotional control; anger/rage, and irritability; loss of self-esteem (I'm no good); ongoing illnesses to talk about feeling ill, loss of appetite (combination of two or more of these).



Duty to Report Abuse & Neglect

We all share a responsibility to protect children from harm. This includes situations where children are abused or neglected in their own homes. As a RP you must promptly report any suspicions that a child or youth has been or is likely to be abused or neglected, and that the parent is unwilling or unable to protect the child or youth to a child welfare worker. The duty to report applies to any child who is, or appears to be, under the age of 19 years.

When making a report to a child welfare worker, it is helpful to include your name, your phone number and your relationship to the child or youth. But you can make an anonymous call if you prefer. The child welfare worker will want to know:

- The child's or youth's name and location;
- Whether there are any immediate concerns about the child's or youth's safety;
- Why you believe the child or youth is at risk;
- Any statements or disclosures made by the child or youth;
- The child's or youth's age and vulnerability;
- Information about the family, parents and alleged offender;
- Information about siblings or other children or youth who may be at risk;
- Whether you know of any previous incidents involving, or concerns about the child or youth;
- Information about other persons or agencies closely involved with the child, youth and/or family;
- Information about other persons who may be witnesses or may have information about the child or youth;
- Information about the nature of the child's or youth's disabilities, his or her mode of communication, and the name of a key support person; and
- Any other relevant information concerning the child, youth and/or family, such as language or culture.

You do not need all this information to make a report. Just tell the child welfare worker what you do know. Time is of the essence in responding, so if you have concerns, do not delay.



1.2 Community Outreach: Awareness, Connections, and Relationship

Increasing Awareness

You are an Ambassador or Representative of Family Support Institute. Always be informing parents/family members and professionals of who and what FSI does. Many RP's feel comfortable speaking to groups of parents, family members and/or professionals. Training is provided if you are uncertain but want to try this. Some examples are:

- **Giving a presentation on the Family Support Institute** – During a presentation you can provide information about who we are and what we do. The FSI office has a package of information including, a premade PowerPoint and tips on customizing the presentations, makes this very easy. Extensive information on how to complete presentations are available at the FSI office.
- **Hosting a Parent/Family Member Support Group** – Learning to host a support group for parents/family members has many benefits, including being able to connect with families and finding common areas of interest. More information on how to begin this process can be acquired from the office.
- **Speaking to Professionals** – Speaking to professionals on a one-to-one basis can assist you in a variety of ways. It can enable you to learn about current topics of interest to families, who have children/family members with disabilities. Examples of these might be waitlists, difficulty in accessing services, building rapport with the school team, etc. Check with the office to see that you have all the updated information on your topic, government issues can change rapidly.
- **Talking to College students** – This can provide valuable information to both you and the students. The student will have the opportunity to learn from you about what is involved in being a parent/family member of a child/family member with special needs. Students in programs or something similar to these: Applied Behaviour Analysis (Autism) program, Early Childhood Education, Supported Child Care, Community Support Worker, Child Care Worker, may be interested.
- **Setting up a display table** – This can be done at places such as a resource fair, local mall, conference or workshop. The office has a display material that you can use if you contact them in advance of your display times.
- **Writing Articles** - Share your talent or learn how to write articles for local and provincial newsletters. The FSI's newsletter POSSIBILITIES welcomes family stories, news from your community, and articles of interest to other families and our community at large. We can also look at including your resources and stories in the monthly RP/RFM Updates that is sent out to other RPs/RFMs.



Establish Community Connections

As we go about our day to day business, it is important to remember that anywhere we go there may be families who could benefit from FSI support. Make yourself aware of local agencies, community services, and resources available to individuals with disabilities by self-educating, researching, networking, reading, and collecting materials.

Below are some suggestions of organizations or individuals to whom you might want to distribute the FSI brochure, your business card or letter of introduction.

- Family doctor
- Infant Development Programs
- Child Development Centre's/Pre-schools/Daycares
- Hospital labour/delivery rooms/Prenatal groups
- Parent, sibling or grandparent support groups
- Crisis lines/Counseling Centre services
- Public Health Units
- Schools – bulletin boards, teachers, special education program coordinators
- Government ministry offices
- Local MLA offices
- Inter-cultural associations
- Advocacy groups
- Non-profit associations, community Centre's, recreation Centre's
- Clubs, Girl Guides, Brownies, Cubs Church groups
- Pediatricians
- University and colleges- Schools of Child Care, Social Work
- Brochure racks and bulletin boards in public places frequented by families

Serve on Committees and Boards

Many RPs join **advisory committees** to provide information to parents/family members, to professionals and to advocate for services in their community. It helps them stay abreast of the information and issues on a particular topic and they know that at least one parent's/family member's voice is being heard. Some examples of committees you may want to consider joining are: School districts (Special Education Advisory), your child/family members PAC, Community Living Associations, Ministry Committees, Supported Child Care, Hospitals, Health Services, and the B.C. Association for Community Living's Education Committee.

We encourage you to share which committees you sit on with the FSI office. Sitting on committees and boards also given you the opportunity to represent FSI and share the FSI resources. This will ultimately lead to higher visibility of FSI in the province, and enable us to support more families in the future.

Others become members of various **boards** with local associations, community groups, etc. The FSI board is made up almost entirely of RPs, representing the province.



1.3 Communication Skills

As a RP you will be communicating with the families, the FSI main office, other RPs from the network, service providers and government agencies. When supporting families the most important skills you will use are your **communication skills**.

When we listen effectively we:

- Communicate acceptance
- Increase trust
- Facilitate problem-solving

A good listener:

- Suspends judgment
- Checks with the speaker to ensure the accuracy of the message received
- Provides an opportunity for the speaker to clarify when necessary
- Gives full attention to the speaker, not interrupting
- Maintains eye contact and shows interest through open body language
- Asks questions
- Paraphrases to ensure understanding

Good listening skills take **discipline, practice and hard work**. Practice on your family and friends. Find someone objective and willing to give you feedback.

You are not listening when:

- You say you understand before you know me well enough.
- You are trying to sort out all the details of my story, unaware of the feelings behind my words.
- You have an answer for my problems before I have finished telling you what it is.
- You cut me off before I have finished speaking.
- You finish my sentence for me.
- You tell me about your experience, which makes mine seem unimportant.
- You are dying to tell me something, or want to correct me.
- You are disturbed by my loaded words or abusive language
- You sense that my problem is embarrassing and you want to avoid it.
- You are communicating with someone else in the room while I am talking.
- You need to feel successful in helping me.
- You refuse my thanks by saying you have not really done anything.

Styles of Communication: Passive, Aggressive, and Assertive

Passive Person	Aggressive Person	Assertive Person
<p>Does not express:</p> <ul style="list-style-type: none"> • Feelings • Needs • Ideas <p>Allows others to infringe on rights</p>	<p>Expresses:</p> <ul style="list-style-type: none"> • Feelings • Needs • Ideas <p>At the expense of others</p>	<p>Expresses:</p> <ul style="list-style-type: none"> • Feelings • Needs • Ideas <p>Without violating the rights of others</p>
<p>Behaviour is:</p> <ul style="list-style-type: none"> • Inhibited • Indirect • Self-denying • Emotionally dishonest 	<p>Behaviour is:</p> <ul style="list-style-type: none"> • Defensive • Hostile • Overpowering • Manipulative 	<p>Behaviour is:</p> <ul style="list-style-type: none"> • Emotionally honest • Direct • Expressive • Self-enhancing
<p>Does not achieve goals and feels:</p> <ul style="list-style-type: none"> • Anxious • Disappointed • Angry • Resentful 	<p>May achieve goals but feels:</p> <ul style="list-style-type: none"> • Self-righteous • Guilty • Frustrated • Alone 	<p>May achieve goals and feels:</p> <ul style="list-style-type: none"> • Confident • Good
<p>Avoids conflict</p>	<p>Not willing to:</p> <ul style="list-style-type: none"> • Compromise • Negotiate 	<p>Willing to:</p> <ul style="list-style-type: none"> • Compromise • Negotiate

Adapted from: The Individual Education Plan, Trainer's Manual, The Massachusetts Department of Education, Special Education Division, 1979.

Assertive Is Based On Balance:

Please be mindful Assertive is **not** the same as Aggressive. Aggressive means **getting** what you want, assertive means **saying** what you want. Assertive requires being forthright about your wants and needs. When you are assertive, you are self-assured and draw power from this to get your point across firmly, fairly and with empathy. Assertive behavior is a skill that can be learned and maintained through practice. Assertive also means:

- Voicing your needs and wants confidently and being able to express them (including the feelings of anger, hurt, vulnerability, etc.)
- Valuing yourself, your rights and your ideas and being able to state them
- Sticking to the problem or situation and not focusing on the person's character
- State feelings as positively as possible and relate them to your needs

Active Listening Techniques: Help the other person speak freely

Statement	Purpose	To Do This	Examples
Encouraging	<ul style="list-style-type: none"> To convey interest To encourage the other person to keep talking 	<ul style="list-style-type: none"> Don't agree or disagree Use neutral words Use varying voice intonations 	Can you tell me more?
Clarifying	<ul style="list-style-type: none"> To help you clarify what is said To get more information To help the speaker see other points of view 	<ul style="list-style-type: none"> Ask questions Restate wrong interpretation to force the speaker to explain further 	When did this happen?
Restating	<ul style="list-style-type: none"> To show you are listening and understanding what is being said To check your meaning and interpretation 	<ul style="list-style-type: none"> Restate basic ideas and facts 	So you would like your social worker to understand and appreciate your situation, is that right?
Reflecting	<ul style="list-style-type: none"> To show that you understand how the person feels To help the person evaluate his or her own feelings after hearing them expressed by someone else 	<ul style="list-style-type: none"> Reflect the speakers' basic feelings 	You seem very upset about this.
Summarizing	<ul style="list-style-type: none"> To review progress To pull together important ideas and facts To establish a basis for further discussion 	<ul style="list-style-type: none"> Restate major ideas expressed including feelings 	These seem to be the key ideas you've expressed:
Validating	<ul style="list-style-type: none"> To acknowledge the worthiness of the other person 	<ul style="list-style-type: none"> Acknowledge the value of their issues and feelings Show appreciation for their efforts and actions 	I appreciate your willingness to try again when you are obviously having a hard time of it.



Listen

When I ask you to listen to me
And you start giving me advice
You have not done what I asked

When I ask you to listen to me
And you begin to tell me why I shouldn't feel that way,
You are trampling on my feelings.

When I ask you to listen to me
And you feel you have to do something to solve my problem
You have failed me, strange as that may seem.

Listen? All I asked, was that you listen:
Not to talk or do - just hear me.
Advice is cheap: 10 cents will get you both Dear Abby and
Billy Graham in the same newspaper.
And I can do for myself; I'm not helpless.
Maybe discouraged and faltering, but not helpless.

When you do something for me that I can and need to do
For myself, you contribute to my fear and weakness.

But when you accept as a simple fact that I do feel what I feel, no matter
How irrational, then I can quit trying to convince you and get about
The business of understanding what's behind this irrational feeling.
And when that's clear, the answers are obvious and I don't need advice.
Irrational feelings make sense when we understand what's behind them

Perhaps that's why prayer works, sometimes, for some people because
God is mute and doesn't give advice or try to fix things.
God just listens and lets you work it out for yourself.

So please listen and just hear me.
And, if you want to talk, wait a minute for your turn;
And I'll listen to you.



2.1 Supporting in Person

Very often, it is appropriate and helpful to support families in person when they must attend a meeting with a professional or service provider to which they feel they would like the support of a RP. These meetings could be with a service delivery team that may include a social worker, child care worker, respite worker, etc. or a school team meeting such as an IEP (Individual Education Plan). If properly prepared for, in most cases, these meetings can be very positive.

Sometimes meetings can be highly emotional and even distressing for parents. The emotional support of having another RP there to balance out the number of professionals may be critical in easing the stress for families. It does not mean you will have to speak for the parent/family member. You may only be there to take notes, or even just witness the dialogue, and it will be important to decide with the family what your role will be in advance.

Meetings

Meetings may be called by parents/family members, the school, school district personnel, or associated professionals to review educational program, safety plans or to resolve an issue.

Preparation for such a meeting is important. Meet with the parent/family member in advance and discuss the meeting agenda, if known, or to develop their own agenda. The parent/family member has the right to ask for the agenda and the names of those who will be in attendance.

Discuss each of the items, helping the parent/family member to look at it thoroughly and coming to some understanding of what the parent/family member wants to achieve at the meeting. When they know their position in advance, communication goes more smoothly and their negotiations are strengthened. If necessary, try role-playing a situation to help the parent/family member get used to communicating effectively and confidently.

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 this meeting. Consider preparing or asking for an agenda.
- Prepare your questions, or document concerns. Keep it brief and focused. Be realistic about what can be covered in one meeting. Decide what materials to bring.
- Know who is attending, what their role and degree of involvement with the child/family member is.
- Invite families support people, therapists etc. and notify the person who called the meeting of their attendance. Make copies of materials for all in attendance what the families position is.
- When possible both parents and/or family members should attend meetings. This may mean school personnel set a meeting time that enables working parents to attend.
- Present examples of what the family wants, for their child/family member. For instance, if presenting a case to the school board, they may find it easier to understand examples of what the family wants.

General Tips for the Meeting:

- Ask clarifying questions and make suggestions where necessary.
- Seek facts and focus on the issues, not the people.
- Use good communication skills.
- Take careful notes.
- Make sure that information presented by professionals is clear and understood by all.
- If financial concerns are expressed by the school, be supportive to the family in their effort to not back down on their request.
- Help the family know their bottom line, where they can trade off and where they won't. Summarize the discussion and review the decisions made.
- Advise the family they do not have to agree to decisions or sign anything they are not ready to. (It is alright to say you need time to think about it or discuss it with your partner/family members.)
- If someone else has taken minutes, ask for a copy.
- Set follow-up meetings if necessary.

Following the Meeting:

- Give the family time for reflection after the meeting. Check how they are feeling. Have some feelings surfaced that you were unaware of at the meeting? If so, take note of them.
- Ask the family if they satisfied with the process of the meeting, the results, the solutions, the strategies? Did they feel listened to?
- Review your minutes and add anything you missed.
- Compare your minutes with minutes of others you have received.
- Is the family clear what the next steps are?
- Ask the family to respond in writing to the person who chaired the meeting (or the principal) outlining the families understanding of major points covered, decisions made, and indicate whether or not the family is in agreement.



RP Statuses

Active RP

All new RPs are placed into **Active status**. This means they understand the roles outlined in the previous pages of this Orientation Binder and fully accept this role.

Inactive RP

Inactive status means that the RP will not have families referred to them as they manage their own life circumstances. It does not prohibit an inactive RP from receiving support from our network. At FSI we want to always support our volunteer network and find ways to keep them strong, healthy and vibrant. This status is thus **“self-determined”** for those RP’s who find they are unable to offer family support for any variety of personal circumstances. An RP can maintain this **status** for up to **one-year** with the possible extension for an additional year, if approved by the RP Committee.

The Provincial office will check in with an inactive RPs *at 3, 6, and 9 months* of becoming inactive to ensure that the RP has the support they need. At the one-year mark, the RP can determine whether they would like to become active, ask for an extension for an additional year or retire. Under extenuating circumstances, the inactive RP may request an extended beyond the two-year period, but will again need the approval by the RP Committee.

Retired RP

The **retired** category is for RPs who choose to discontinue with active involvement in our network such as attending the Training Weekends and supporting other families. This status is self-determined. Once the RP has decided to retire from the volunteer position, they will no longer receive the confidential RP information. Should a retired RP want to become an RP again they would re-apply to the Provincial office to begin the process of becoming an active RP again.

Administrative Inactive RP

This category is designated by the Provincial office. It is for RPs who have not had contact with the FSI offices for more than 1 year, despite frequent attempts by the FSI Team. The FSI office will make every effort to contact the RP at 3, 6 and 9-month intervals. This may include individuals whose phone numbers are out of service, their mail is returned and emails have bounced back. It is the responsibility of the RP to notify the FSI offices of any changes to their contact information. Failure to do so may put their name under review with the RP committee who will determine – along with the FSI team - if retirement from the RP network is warranted. A retired RP can always re-apply to the Provincial office to begin the process of becoming an active RP again.

III. Parents/Family Members with Special Needs

Some parents/family members have special needs themselves. This may mean you adjusting to their special need for communication and understanding or it may mean you helping them to find out what special services they may need. Some examples of special needs you may encounter and some tips to help you make things go easier for them.

Visually Impaired, Low Reading Level, English as a Second Language

A parent/family member may not be able to read printed literature for many reasons. Find out whether or not they have reading services available. If not, the materials can be taped. If you cannot do this, check with the office, or in your community to find someone who can.

You can decide to:

- Discuss materials with the parent/family member or ask a representative of the source to explain, i.e., hospital, social worker, etc.
- Rewrite materials using simpler language
- Encourage parents/family members to talk with medical staff
- Repetition may be helpful
- Identify a person to provide interpreting services
- Obtain translated materials.

Remember, parents/family members may be embarrassed at their difficulty with reading. Emphasize that the importance of knowing what is happening is more important than knowing every word. Encourage them not to withdraw. Help them explore alternative ways to obtain information.

Hearing Impaired

Find out what supports are needed for you to communicate with this parent/family member, a friend, a signer, meeting in person, or do they need to get special equipment for their phone so they can hear you. You must address any communication barrier first so support can take place. Reprints and library materials can be especially important to parents with a hearing impairment.

Wheelchair User

A parent/family member in a wheelchair may have a difficult time with transportation or access to appointments, visits, or in their home. Discover what their particular needs are and help the parent address them.

Adapted from: Parent to Parent Training Guide, Parent to Parent, King County, Seattle, Washington.

IV. Culturally Diverse Families

You may be asked to support a family whose cultural background is very different from your own. There may be significant differences in language, communication styles, family values, etc. that make it a challenge for you to understand and support this family. Here is some basic information about how to become more knowledgeable about cultural differences. These strategies will take time to work on, so in the meantime, if the task is overwhelming to you, ask the office for help and guidance.

1. Improve your **knowledge** base about new cultures.
2. Develop your **skills** to ensure effective interactions with culturally different families.
3. Become more **self-aware** of your own opinions, attitudes and assumptions about various cultures.

Knowledge

What is important knowledge to have?

- Specific information on:
 - Past history (i.e. refugees)
 - Family make-up/structure
 - Child rearing practices/expectations/values
 - Attitudes towards disability
 - Socioeconomic background
 - Language spoken, slang used
 - Inherited customs
 - Learning styles/Ways of thinking
 - Norms and beliefs (i.e. appropriate behavior)
- Community support and other resources available to the family (i.e. Cultural Organization, extended family, place of worship, school, traditional medicine).
- Specific constraints on time, setting and resources for each family.
- How your own culture (professional training and upbringing) relates to the family's culture (similarities and differences).
- The type of professional expertise that is valued by the culture (i.e. academic, physical, medical).
- Resources that are available to you as a professional (i.e. cultural organizations, families).

How do you improve your knowledge base?

- Workshops
- Connecting with your local cultural resource centre or person
- Accessing relevant literature (i.e. library, families)
- Experience

Skills

What are important skills to have?

- Using appropriate working styles to establish trust and rapport (i.e. direct vs. indirect, taking time for social interactions, acknowledging pleasantries like removing shoes, taking tea, etc.)
- Reading verbal and non-verbal cues to ensure accurate assessment of needs.
- Observing, understanding, and accurately reporting particular cultural behaviour.
- Interacting and advising families on a course of action (i.e. treatment) that respects cultural expectations and practical limitations.
- Using translators and cultural informants effectively.

How do you improve your skills?

- Improve your knowledge and self-awareness.
- Specific training when available
- Take time to build relationships

Self-Awareness

What are important areas of self-awareness?

- Identifying biases in your own culture (attitudes and expectations from professional training and upbringing).
- Being sensitive to stereotypes of different cultures
- Being aware of your own personal and professional boundaries and how these impact multicultural families (Have you done all that you can do?)
- Being able to accurately judge different values and practices (i.e. some traditional medicine is respected while others may not be).
- Realistically estimating your own limitations and degree of knowledge and seeking help or additional knowledge if needed.

How do you improve yourself awareness?

- Workshops
- Openness and willingness to work with families from different cultures
- A basic respect for people and differences
- A desire to do the best that you can for children and families.
- Being non-judgmental

Source: Sunny Hill Cross Cultural Committee, Community Care Foundation and BC Health Research Foundation sponsored workshop "Working with Culturally Diverse Families of Children with Disabilities", Vancouver, B. C.



V. A Sense of Grief: The Stages

It is widely accepted that grief is a response to loss or separation. Having a child/family member with a disability can be the loss of a dream; the perception of what a child/family member should be. At the time a disability is identified and at various stages through the development of their child/family member, parents/family members are confronted with issues of loss and respond with various emotions (guilt, anger, denial, anxiety, and depression.) The experience is natural, painful and healthy.

The process is natural. Feelings and emotions are human responses. They are not right or wrong; they just are. The identification of a disability triggers emotions in parents/family members that are natural in a situation that is new and uncharted. Prior to diagnosis each parent/family member subconsciously holds a road map of life for themselves and their children/family member. At the time of diagnosis and at various points along the way, they find themselves on a road not listed on their map and no way to turn back. When this happens, it is natural to feel anxiety about choices that need to be made, anger at the mapmaker, guilt for possibly taking a wrong turn, fear of the unknown, and possibly a time spent denying that this could even be happening. To respond otherwise would be unnatural.

The process can be painful. A parent/family member may feel out of control, unable to deal with this new set of circumstances, overwhelmed with sadness or anger. The intensity of emotions may be uncomfortable for those who are interacting with a grieving parent/family member. There is a tendency for others to want to alleviate the pain or at least diminish the intensity. To do so is to deny the parent/family member their search for a new path.

The process is healthy. Through the grief experience, parents/family members may reevaluate life. They often create new maps for themselves and their children/family members by redefining their destination, asking directions, and finding new roads. Through the process, they develop strengths and skills, discovering values that were previously unknown to them. Through the pain comes growth and purpose. Parents/family members find themselves no longer at a crossroads with no place to turn but with a revised map and new roads to travel. The roads are neither better nor worse, just different.

Not only is the process natural, painful and healthy but it is also an individual process. Each person experiences it in his or her own way and in his or her own time. No one can or should do it for them, but others can walk with them as they go.

Be prepared to reevaluate your own map as you help others to define theirs. Mapping out the destination is an ongoing task, but each detour is accomplished with a little fewer struggles than the first. Grieving never ends only the intensity changes. Remind yourself of the skills, strengths and values you have found in yourself since you first stood at the crossroads. Perhaps the fact that you have at least traveled part of the way will give others the strength to begin their own journey.

Source: Key Parents, American Society for Deaf Children. Grief information taken from ideas and theories of Kenneth Moses.

Welcome to Holland

“When you’re going to have a baby, it’s like you’re planning a vacation to Italy. You’re all excited. You get a whole bunch of guidebooks, you learn a few phrases in Italian so you can get around, and then it comes time to pack your bags and head for the airport—for Italy.

“Only when you land, the stewardess says ‘Welcome to Holland’.
You look at one another in disbelief and shock, saying ‘Holland?
What are you talking about? I signed up for Italy?’

“But they explain there’s been a change of plans, and you’ve landed in Holland, and there you must stay. ‘But I don’t know anything about Holland! I don’t want to stay!’ you say”.

“But you stay. You go out and buy some new guidebooks, you learn some new phrases and you meet people you never knew existed. The important thing is that you are not in a filthy, plaque-infested slum full of pestilence and famine. You are simply in a different place than you had planned. It’s slower paced than Italy, less flashy than Italy, but after you’ve been there a little while and you have a chance to catch your breath you begin to discover that Holland has windmills. Holland has tulips. Holland has Rembrandts.”

“But everyone else you know is busy coming and going from Italy. They’re all bragging about what a great time they had there and for the rest of your life, you will say: ‘Yes, that’s what I had planned.’”

“The pain of that will never, ever go away. You have to accept that pain, because the loss of that dream, the loss of that plan, is a very, very significant loss. But if you spend your life mourning the fact that you didn’t get to Italy, you will never be free to enjoy the very special, the very lovely things about Holland.”

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Celebrating Holland – I'm Home

I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I'd planned. I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger, the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends. Some of these fellow travelers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn't so bad. I think that Holland is used to wayward travelers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land.

Over the years, I've wondered what life would have been like if I'd landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest. And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its tulips, windmills and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveler and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn't planned. Yet I am thankful, for this destination has been richer than I could have imagined!

Poem by Cathy Anthony. Cathy Anthony is a parent, advocate and presently the executive director of the Family Support Institute in Vancouver, BC (www.vcn.bc.ca/bcacl/fsi.htm)

VI. Skills I Can Develop Overtime

❁ **Communication:**

Develop communication skills such as, reflective listening, empathy, understanding, assertiveness, verbal and non-verbal awareness, public speaking, observation and feedback, conflict resolution, letter writing, advertising, writing and telling my own story.

❁ **Family Support:**

Develop good family support skills such as, how to respond to requests for assistance, making referrals, being prepared to provide support; problem solving skills, respecting confidentiality, encouraging independence.

❁ **Organizational:**

Develop reasonable organizational skills to handle increased workload in family and have easy access to information. Develop filing, message centre, date-book, , etc. Respond promptly and keep commitments.

❁ **Networking:**

Being able to increase awareness and have influence; be familiar with local resources, establish community connections, serve on boards and committees, promote FSI and raise the profile of people with disabilities and their rights.

❁ **Advocacy:**

Being able to work collaboratively and cooperatively with professionals and other families. Develop skills in conflict resolution, written presentations and briefs, letter writing.

❁ **Presentation/Facilitation:**

Develop skills in public speaking, making presentations, writing letters and briefs, facilitating groups and workshops.

❁ **Personal Development:**

Being willing to develop self-awareness through values clarification, self-awareness exercises, understanding emotions and impact on others, maintaining life balance, developing personal goals, doing own grief work.

❁ **Research:**

Being able to support a family in finding resources is an important skill to develop. Each family is unique in the supports they require and it is up to you as an RP to keep yourself current. You may want to read research studies and follow current event to understand what is important to families in today's environment.

These skills support the following duties RPs/RFMs may be involved in over time. The most important skills every RP/RFM will need to develop are good communication and family support skills. Good communication skills serve us in all of our roles and every RP/RFM who is active is usually involved in supporting families, while other roles are seen as optional and can be developed as a person becomes ready.



How can you be a skilled support person?

Becoming a skilled support person takes time to develop. Some areas to explore on your own:

- **Are You In Touch with Your Emotions?**
 - Express emotional states freely
 - Able to describe emotional states accurately (as opposed to never describing feelings)
- **Are You Understanding of Emotions?**
 - Able to talk about your losses
 - Have gained necessary perspective so as to assist others
 - Able to recognize and handle difficult emotions in others
- **Do You Have Effective Communication Skills?**
 - “Own” feelings, ideas, inferences, and evaluations
 - Aware of non-verbal cues
 - Able to clearly convey ideas
- **Are You Self-Aware?**
 - Solicit feedback, seek growth opportunities and chances to learn about one’s self
 - Have a accurate self-image, “humble”
 - Are relaxed, in touch with self (as opposed to artificial, “tight”)
- **Are You Aware of Your Impact on Others**
 - Can you accurately report impact on others (as opposed to unaware of how actions affect others)
 - Put your own thoughts and feelings on hold when appropriate
 - Understand difference between support and advice.
- **Do you Listen Actively?**
 - Listen with empathy and compassion
 - Avoid “roadblocks”, judging, teaching
 - Encourage and create safe “space” for others’ comments
- **What Values Do You Hold?**
 - Convey positive, realistic attitude regarding your own child/family member
 - Respect others’ ability to solve their own problems
 - Non-judgmental, tolerant of others feelings
 - Sincere and truthful
 - Appreciates others’ values and cultural differences

Source: National Fathers’ Network and Parent-to-Parent, King County, Seattle, Washington.



VII. Forms you Need and Where to Find Them

Once you have logged into the RP page on www.FamilysupportBC.com you can find a number of different forms that are useful.

- RP directory forms – these need to be filled out when you have acquired new skills or your contact information has changed. The office may periodically ask you to update these forms for office use.
- FSI Reimbursement / Expense forms for RP – Did you know there are expenses you can write off? Please read the policy booklet to make sure the expense fits the guidelines.

VII. Quick Reference: Useful Websites

- www.findsupportbc.com
- www.inclusionbc.org
- www.communitylivingbc.ca
- www.rcybc.ca
- www.autisminformation@gov.bc.ca
- www2.gov.bc.ca/gov/content/family-social-supports/services-for-people-with-disabilities/supports-services/advocate-for-service-quality
- www.keltymentalhealth.ca/
- www.foundrybc.ca/
- www.cdss.ca/
- www.rarediseasefoundation.org
- www.workbc.ca
- www.disabilityalliancebc.org
- www.plan.ca
- www.specialolympics.ca
- www.challengerbaseball.ca
- www2.gov.bc.ca/gov/content/governments/organizational-structure/ministries-organizations/ministries/children-and-family-development

