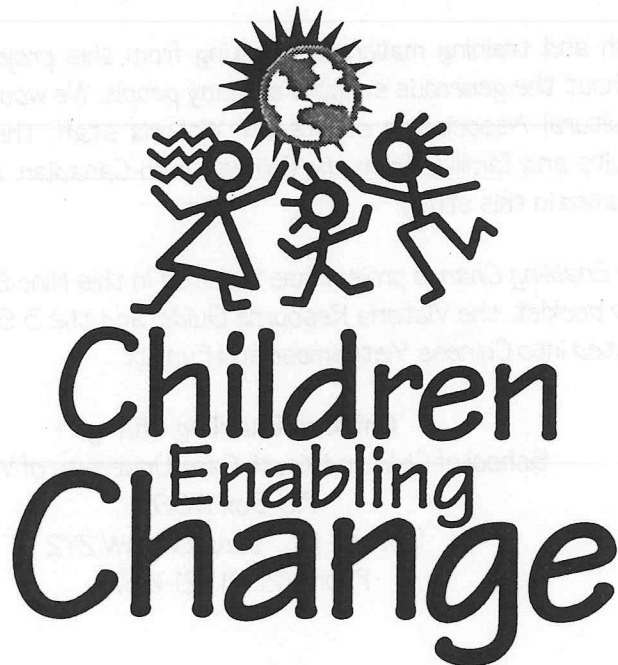


# MANUAL



This manual describes a nine step  
Education, Advocacy, and Action Plan  
for your community to follow which connects  
families who have children with disabilities,  
community support agencies,  
and health service professionals.

# Acknowledgments

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The research and training materials resulting from this project would not have been possible without the generous support of many people. We would especially like to thank the Inter-Cultural Association of Greater Victoria staff, the professionals, and the children, adults and families from the Chinese, Indo-Canadian, and African communities who participated in this study.

The *Children Enabling Change* project has resulted in this Nine Step Action Plan Manual, the Overview booklet, the Victoria Resource Guide, and the 3 Step Brochure, which has been translated into Chinese, Vietnamese and Punjabi.

## **Children Enabling Change**

School of Child and Youth Care, University of Victoria  
P.O. Box 1700  
Victoria, BC Canada V8W 2Y2  
Phone (250) 721-6471

## **Manual Design**

Dr. Philip Cook, Project Director  
Michele Cook, Project Coordinator

## **Writer: Overview and Manual**

Lynette Halldorson

## **Editing and Graphic Design**

Laura Bramly • Synergy Communications, Victoria  
Lis E. Bailly • Portfolio Art Services, Victoria

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# The 9 Step Community Action Plan: Introduction

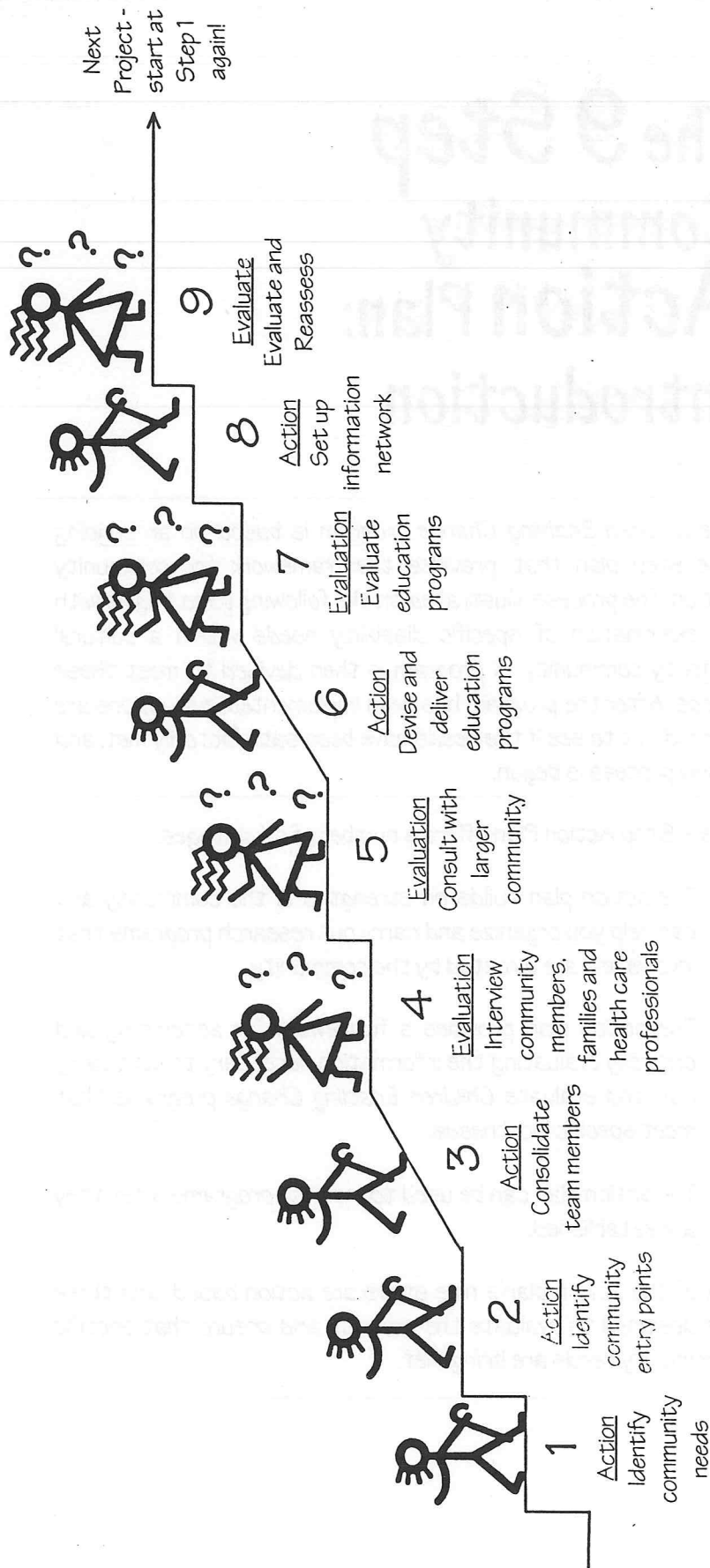
The *Children Enabling Change* program is based on an ongoing nine step plan that provides the framework for community action. The process, illustrated on the following page, begins with an examination of specific disability needs within a cultural minority community. A program is then devised to meet these needs. After the program has been implemented, evaluations are carried out to see if the needs have been satisfactorily met, and a new process is begun.

The 9 Step Action Plan offers a number of advantages:

1. The action plan builds on strengths in the community and can help you organize and carry out research programs that involve and are directed by the community.
2. The action plan provides a framework for assembling and critically evaluating the information necessary to plan, carry out, and evaluate *Children Enabling Change* programs that meet specific local needs.
3. The action plan can be used to monitor programs after they are established.

Six of the action plan's nine steps are action based, and three are designed to evaluate the program and ensure that specific community needs are being met.





## The 9 Step Community Action Plan

## Overview Booklet

Prior to reading this Action Plan Manual, please read the Overview booklet included in the front cover pocket of this manual. The Overview will provide you with a thorough background on Community-based Rehabilitation and the *Children Enabling Change* program, and is essential for gaining a full understanding of the nine step program contained in this manual.

## Introduction to the Action Plan Manual

The contents of this manual are divided into nine sections, one for each step of the Community Action Plan. Step 4 contains an additional section: The Community Participation Research Primer.

Each step of the Community Action Plan is defined as being either an action step or an evaluation step. In this manual, action steps are identified with the following icon:



Evaluation steps are identified with this icon:



The sections describe in detail the tasks, responsibilities, and people involved within each Action Plan step. They provide valuable information about "How to Climb" each step, based on the experiences of the Project Director, Project Coordinator, project staff, and community participants of the original *Children Enabling Change* program.

## Additional Information

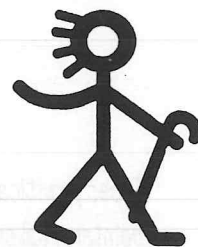
If you would like additional information on the *Children Enabling Change* project, or would like to let us know how your project is going, we would be pleased to hear from you. Please contact:

Dr. Philip Cook, Project Director  
School of Child and Youth Care  
University of Victoria  
P.O. Box 1700  
Victoria, BC V8W 2Y2  
Phone: (250) 721-6471

Inter-Cultural Association of Greater Victoria (ICA)  
200 - 2504 Government Street  
Victoria, BC V8T 4P7  
Phone: (250) 388-4728

# Step 1:

## Identify the needs of the community and its health care workers



Step 1 is an action step

In community-based programs, participation begins with the direct needs of community members. It may take an outsider with some knowledge of rehabilitation and skill in organizing people to get things started, but it is the community members themselves, especially children and other persons with disabilities and their families, who make the decisions about their own programs.

The first step of the *Children Enabling Change* program, therefore, is for an individual or organization with an interest in this issue to speak with families with a child with a disability, persons with a disability, and other interested community members. The purpose of these discussions is to find out whether there is a need and desire for improved culturally sensitive support of children with disabilities and their families in relation to other community needs.

Discussions with rehabilitation professionals (health care workers) are also important. The purpose of these discussions is to find out:

- a) whether they feel that the needs and desires expressed by the community are being met, and
- b) what experience the professionals have in interacting with cultural minority children, families, and other community members.

First, speak with key community members

Then, speak with health care workers



# How to Climb Step 1

These practical pointers, taken from successful *Children Enabling Change* programs, will assist you in planning for your own community program.

The research findings of the first *Children Enabling Change* program highlight two important points to consider when working on Step 1:

## ✓ An Existing Community Organization Can Provide a Strong Foundation for Step 1

It is important to build the *Children Enabling Change* program on existing community strengths. A culturally-focused and/or service-oriented community organization with established and trusted links to cultural minority families provides an ideal base from which to build community participation in these talks, particularly if this organization plays an active role in health promotion. In the first *Children Enabling Change* program, the Inter-Cultural Association of Greater Victoria (ICA) provided the foundation for contacting key community members to attend the community-based talks. The Queen Alexandra Centre for Children's Health (QACCH) and the School of Child and Youth Care, University of Victoria, provided the foundation for organizing these initial talks with health professionals.

## ✓ A Committed Facilitator Plays an Indispensable Role In All Stages of the *Children Enabling Change* Program

The importance of a committed facilitator who will guide and facilitate community involvement in the 9 Step action plan cannot be overstated. The first *Children Enabling Change* program was fortunate to have sufficient funding to hire a committed facilitator who had a significant amount of experience with multi-cultural communities both in Canada and elsewhere in the world, and who was also a community rehabilitation professional. We realize that a person with these qualifications may not be readily available in your community, and that your community may not be able to access funding to pay someone to act as Project Coordinator. However, if you contact existing community development and service organizations in your community, you may discover that there is someone in your community who is already employed to facilitate community-based programs. If there are no community development organizations in your community, perhaps a charitable or service

organization could offer some support. A committed Project Coordinator, whether paid or volunteer, who has the trust and respect of your community, and who is willing to interact with both interested community members and health professionals, will add stability and focus to your *Children Enabling Change* program, and contribute to the quality and strength of your activities throughout.

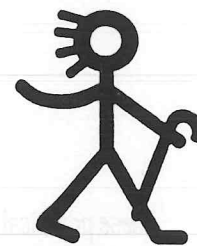






# Step 2:

## Identify appropriate community entry points

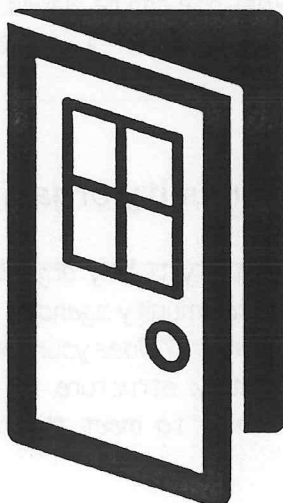


Step 2 is an  
action step

The primary purpose of Step 2 is to ensure that the *Children Enabling Change* program is introduced into the community in a culturally sensitive manner. This is accomplished by forming an initial community interest group with the objective of identifying culturally appropriate entry points upon which to build the community's ownership of the program. Ask the informal community contacts spoken to in Step 1 to suggest other community members who could join you in forming this community interest group. Look to the following community members:

- children with disabilities and their families, and
- other community members in need of special support.

Form an initial  
community interest  
group to identify  
appropriate entry  
points



# How to Climb Step 2

These practical pointers, taken from successful *Children Enabling Change* programs, will assist you in planning for your own community program.

The first *Children Enabling Change* program involved three different communities that participated in the program: the Chinese-Canadian and Indo-Canadian communities of Victoria, and the African-Canadian community of Vancouver. To assist in identifying entry points to the communities, the community interest groups of this first program found that there were four important questions to answer:

1. What is the cultural make-up of this community?
2. How is this community organized?
3. What are the priorities and development needs of this community?
4. What appropriate entry point can be identified from the answers to the first three questions?

These four questions might be of use to you in taking Step 2 to your cultural community. They are explored in more detail below.

## Question 1: Cultural Make-up

### What is the cultural make-up of this community?

Every community is unique. What are the cultural values and background of your community? What are your community development priorities? What are the cultural values and beliefs around disability? What role can be played by the family and the child or other person with a disability in community development?

## Question 2: Community Organization

### How is this community organized?

Is your cultural community tightly organized, or perhaps less organized? Are there community agencies operating in support of your cultural group or not? Does your community see itself as having a distinct identity, structure, or geographic location? What organizations exist to meet the needs of people with disabilities?

For example, at the time of the first *Children Enabling Change* project, the Chinese community in Victoria had a strong infrastructure with established organizations such as the Chinese Consolidated Benevolent Society and the Chinese Lions' Club, churches, and other structural organizations that handle identifiable functions for the community. The African community in Vancouver, on the other hand, was a younger and less established cultural community with almost no identifiable organizations or infrastructure.

### What are the priorities and development needs of this community?

What developmental stage is your community at? If your community has been established in Canada for a long time, it is probably at a very different developmental stage than a community comprised primarily of recent immigrants to Canada. If your community is only recently established, you may have very few or no community development programs or organizations. It is important to find out whether your community is ready for a community-based rehabilitation program. Is this one of your community's priorities? Are issues around finding work, obtaining education, or general health care of pressing concern? Could opportunities be created to include disability issues with these concerns?

For example, at the beginning of the first *Children Enabling Change* project, Victoria's Latin American community was chosen as a potential partner in the project. However, issues concerning refugees, victims of torture, and families with parenting issues were much more pressing for this community at that time. While community-based rehabilitation can be a vehicle to address some of these issues, the community was not yet prepared to focus on disability issues. Also, the community lacked structure, and did not consider itself to be an identifiable community with sufficient organizational strength to take on and sustain this kind of program. Therefore, although the Victoria Latin American community participated in the initial discussions of Step 1, by the conclusion of Step 2 they decided that their community wasn't yet prepared for this type of program.



### Question 3: Priorities and Development Needs





## Question 4: Entry Points

What appropriate entry point can be identified from the answers to the first three questions?

Entry points should be child-focused in most instances, as most communities are more motivated to start with children's disability issues.

What follows are the answers to the first three questions and practical examples of appropriate entry points identified in Step 2 of the first *Children Enabling Change* program.

### Entry Point: Victoria's Indo-Canadian Community

**1. Culture:** The Victoria Indo-Canadian community had a strong cultural ethic around helping people with disabilities. This was reflected in discussions with Sikh and Hindu seniors, who wanted to help people with disabilities. While their focus was primarily on support for seniors, they were interested in talking about strategies to support everyone with disabilities, including children. Through discussions with Sikh seniors, we found out that there were quite a few mothers concerned about the issue of disability. These mothers wanted to help other mothers who had children with disabilities, and to get involved in some of the activities that focused on seniors. This is an example of a community with an established value of helping people with disabilities. Negative feelings around issues of disability did not pose a major challenge at the community level.

**2. Structure:** There was a good deal of structure in Victoria's East Indian Community: Hindu Prashad, the Hindu Temple, the Sikh Temple, the Sikh Seniors' Association, etc. The community also had strong links to the Inter-Cultural Association of Greater Victoria (ICA).

**3. Priorities:** Seniors' issues were right at the top of the community development list, and the link established between seniors' and children's disability issues tied the issue of disability in general into broader community developmental strategies.



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**4. Entry Point:** The Step 2 entry point chosen was to link children's disability issues to the seniors' issues. This raised the priority of the children's disability issue, so that they could be addressed simultaneously with high-priority issues for seniors. This entry point proved to be effective in terms of a community development strategy, and helped to raise awareness and gather support around children's disability issues.

**1. Culture:** The Victoria Chinese-Canadian community embraced the ethic or value of helping seniors with disabilities, however there was resistance to talking about or helping children with disabilities. There was a significant amount of negative feelings expressed against children with disabilities.

**2. Structure:** This was a well-established community with a strong infrastructure: the Chinese Public School, the churches, the Lions' Club, the Chinese Benevolent Association, etc.

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**3. Priorities:** Disability issues were not a high community priority. In fact, as a general community priority it ranked very low, but within a small sector of the community, particularly those families who had experience with children with disabilities, there was a priority to help other families. Families who had children with disabilities were acutely aware of the cultural stigma involved, and didn't know about the resources available to them; this group was also eager to take action. Therefore, while community members in general were not keen on getting involved in a big community development strategy, there was a small sector of the community that was interested in low-profile community development action focused on children's disability issues.



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**4. Entry Point:** This community focus group decided to start with the relatively small and directly involved sector of the community, rather than attempt to address children's disability issues in the larger community development arena where there was resistance. This is an example of choosing an entry point within the larger community where people were receptive and ready, in this case with the families of children with disabilities.

**Entry Point:**  
Victoria's  
Chinese-Canadian  
Community



The project team began by setting up a family support group, talking to some of the mothers and care providers, and trying to bring the mothers together with resource people from ICA.

## Entry Point:

### Vancouver's African- Canadian Community

**1. Culture:** Many cultural groups are represented within the “umbrella” of the African community (at one meeting, at least four different African languages were spoken), which made it impossible to single out a common value or ethical approach around the issues of children with disabilities. In addition, this was a relatively new group of immigrants to Canada, which posed unique challenges. There were many disability issues in the community that were quite specific to distinct cultural groups — for example, scarring, traditional types of disabilities such as the filing of teeth that hindered efforts to speak English or to be understood, female genital mutilation, refugees with disabilities caused by torture or by war, etc. The common theme or value across all of these groups was that they all wanted more information about existing services and programs to help their children. They wished to understand the support options available to them.

**2. Structure:** At the time of the first *Children Enabling Change* program, Vancouver's African-Canadian community had very little structure. Almost all community members were recent immigrants to Canada. There were several cultural organizations that were assisting the community, such as Mosaic and the Immigrant Settlement Services (ISS).

**3. Priorities:** In all cultural groups, there was a common priority to seek information, and a generally high level of motivation to access services and to help children.



**4. Entry Point:** This community focus group decided to use the larger cultural organizations, such as ISS, as the common entry point, and to focus on the issues of information dissemination. The group decided that the action of disseminating information dissemination on disability services provided a strategy to bring these communities together, and in this case the strategy itself became the entry point for community development. Although the different African



community groups had identified very few shared community development issues, the common issue of children with disabilities became the strategy to bring together African communities that usually did not communicate with each other.

**1. Culture:** The Victoria Latin community expressed a general value around helping people with disabilities.

**2. Structure:** At the time of the first *Children Enabling Change* program, there was very little cohesion or organization in this community. Key community members had attempted for a year to bring the community together with a focal theme, but had not been successful. In many ways this was a community in crisis.

**3. Priorities:** Issues of disability were a very low priority. The community expressed a pressing need to deal with issues of refugees, victims of torture, family abuse and family violence, and advocacy for women. Currently, disability was a low profile issue because the Latin community was relatively new to Victoria, and current immigration laws don't allow many children and adults with disabilities into the country. The issue may surface as a higher priority in another 5 or 10 years.



**4. Entry Point:** The strategy of the Latin focus group was to suggest that ICA work with the community on pressing community development issues, and to keep disability issues as part of ongoing discussions. Under these circumstances it was most helpful to work with a community organization that could keep disability issues in mind for future development work. A Disability Project remains an option for the future as community priorities change, while attention focuses on the pressing needs of today.

**Entry Point:**  
Victoria's Latin-  
Canadian  
Community

Entry Point  
Victims/Later  
Candidates  
Community

1. Citing the fact that the community is a diverse  
and vibrant one, the report states that the  
community is a place where people are  
able to live and work together.

2. The report states that the community is a place  
where people are able to live and work together.  
The report states that the community is a place  
where people are able to live and work together.  
The report states that the community is a place  
where people are able to live and work together.

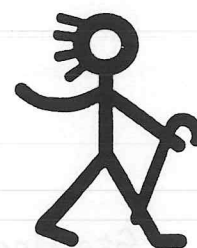
3. The report states that the community is a place  
where people are able to live and work together.  
The report states that the community is a place  
where people are able to live and work together.  
The report states that the community is a place  
where people are able to live and work together.



4. The report states that the community is a place  
where people are able to live and work together.  
The report states that the community is a place  
where people are able to live and work together.  
The report states that the community is a place  
where people are able to live and work together.

# Step 3:

## Consolidate key team members from the community and health care institutions



Step 3 is an action step

Step 3 involves identifying a Project Coordinator to recruit and coordinate participants, facilitate group meetings, and liaise between the community and health care institutions.

Identify a Project Coordinator

## How to Climb Step 3

It is important to designate one person as the central Project Coordinator for a *Children Enabling Change* project. Because there are often several different community development projects on the go within a cultural minority community, we suggest that any agency attempting a project like this should find one person to take on the main responsibility of overall project coordination. Preferably this person will be a well regarded member of the minority culture embarking on the program. Alternatively, the Project Coordinator could be someone within the contact organization who:

- is a community member, or
- has had **extensive cross-cultural experience**, and
- **understands the project research methods** thoroughly enough to be comfortable **orienting and supporting** members of the community research team.

These practical pointers, taken from successful *Children Enabling Change* programs, will assist you in planning for your own community program.

Even if your agency isn't able to fund a Project Coordinator to be involved full-time in this project, at least be sure to **designate one person or a division within the organization to assume the lead organizing responsibility** for the project.

## Steering Committee

### Steering Committee Membership

The Project Coordinator is responsible for putting together and for facilitating, under the guidance of the community interest group (Step 2), a loosely knit **Steering Committee** made up of representatives from all the different aspects of the project. The Coordinator will call this committee together periodically to update information and to strengthen the Steering Committee's ongoing involvement in the project.

Members of the Steering Committee should include:

- children with disabilities and their families,
- other community members with disabilities,
- cultural organizations,
- extended family members,
- community leaders,
- health agencies,
- community health care workers,
- service organizations,
- research experts (in the first project, these were drawn from the School of Child and Youth Care, University of Victoria).

The Steering Committee members can come together as a whole group or in separate sub-groups depending on the issues to be discussed. In order to maintain clear communication amongst all members of the Steering Committee, it is essential that the Coordinator (and as many community interest group members as possible) attend all meetings and that everyone is informed about the outcome of each meeting.

## Support for Family Participation

It is sometimes difficult to get families to participate in meetings. In order to **encourage family members to participate** in the Steering Committee meetings, the family members were contacted by phone by an appointed community liaison person. The Project Coordinator then sent a letter and made a second follow-up phone call to verify their plans to attend the meeting. Food and child care were provided, as well as transportation to and from meetings for some participants.

## Community Participation Research Interviewers

The Project Coordinator will need to assemble a team of Community Participation Research Interviewers, comprised of a sufficient number of **community liaisons to conduct the community research interviews** required in later program steps. Training of community participation research interviewers is discussed in detail in Step 4. In brief, it is crucial to find researchers who:

- **speak the language of the community.**
- have or are able to **establish respect and trust with the families of children with disabilities** in that community, and
- **are familiar with the community's cultural values.**

It is also helpful if researchers have some understanding of research methodology; however, the Project Coordinator should be able to orient someone with a strong base in community development and outreach skills to conduct the project research with tact and competence. If for some reason a researcher is unable to complete the program, the Project Coordinator will have to **find an appropriate replacement** and ensure that the new researcher is fluent in the community's language, culturally sensitive to the community, acceptable to community members, and fully oriented to the project and appropriate research methods and format.

In order to keep the program running effectively, **clarity of communication** is a key issue. It is important that the Project Coordinator be **proactive**, and **keep written records** of key conversations, meetings and community decisions and instructions. Written notes and minutes of meetings, as well as a record of meeting attendance, should be shared amongst all team members.

Many former community-based rehabilitation strategies were designed for projects in developing countries, where people are often not as pressed for time as most Canadians. One of the main challenges facing the first *Children Enabling Change* Project Coordinator, was to **adapt the project to people's already over-full schedules**. This included not only research personnel involved in the project, but also the people being interviewed as

## Communication

## Scheduling Strategies

family research contributors. The strategies adopted by the Project Coordinator to adapt the project included:

- establishing regular meeting times at the beginning of the project;
- providing child care;
- serving food;
- providing transportation to and from meetings;
- keeping meetings focused and meaningful;
- ensuring meetings were interactive; and
- providing feedback to participants after the meeting.

## Regular Meeting Times

The Project Coordinator should establish **regular dates and times for Steering Committee and research team meetings** at the beginning of the program, rather than trying to organize these meetings along the way. The Project Coordinator will find meetings easier to administer in this manner. The research team should meet once a month at least to ensure that everything is on track and that the researchers are receiving the support that need. It is very important that the full Steering Committee meet at least once every three months, to review what has happened and guide the process. These meetings help to:

- maintain accountability to the community.
- strengthen communication and feedback.
- enhance broader community ownership of and involvement in the project, and
- keep participants involved and motivated.

They also serve to **clarify any potential misunderstandings** that may arise regarding the intent and outcome of the research and project itself.

## Continuation of the Project

Finally, it is important for the Project Coordinator to **prepare for a community development organization to continue to coordinate the project once the nine steps are completed.** For example, the Project Coordinator of the first *Children Enabling Change* project has recommended that the ICA take over coordination of the Victoria programs.

# Step 4:

## Carry out family, community, and health care professional interviews



Step 4 is an  
evaluation  
step

During Step 4, the Research Team conducts research interviews that will shape *Children Enabling Change* to meet the specific needs of the community.

Conduct research  
interviews to identify needs

Some community members may hold negative stereotypes about research, and not understand its purpose and benefits. These people may not want to include this step in a community disability program, feeling that research is too intrusive, manipulative, or simply unnecessary. In our experience, however, research has proven to be an indispensable tool to help identify community needs and resource areas. It also serves as a means of facilitating greater community understanding and involvement in the project and evaluation. A simple "how to" primer on carrying out basic participatory research follows Step 4, to help you and your team put this important step into action.

Community  
Participation  
Research:  
A Basic  
Primer

The primer explores four key community participation research questions:

1. **Information:** What information do you need, and how will you collect it?
2. **Interviews:** What process is needed to conduct research interviews?
3. **Participants:** Which community members will become your community research interviewers? Who will be interviewed?
4. **Analysis:** How do you analyse the information collected, and use it to benefit your community?





# How to Climb Step 4

These practical pointers, taken from successful *Children Enabling Change* programs, will assist you in planning for your own community program.

The "How to Climb this Step" portion of Step 4 is divided into two sections:

## Section A: Training Community Participation Research Interviewers

This section contains practical suggestions to guide the training of the community-based researchers who will conduct the research interviews in your community.

## Section B: Interview Groups

This section outlines three different groups within your community who could be research participants in the community participation research interview process, and states the purpose for interviewing each group.

## Section A: Training Community Participation Research Interviewers

The following points are included to help the Project Coordinator train community-based research interviewers who may have little or no background in this area:

### 1. Why is research important?

1. Because of the potentially sensitive nature of disability issues, it is especially important that interviewers receive a thorough orientation to the project, the interview process, and culturally appropriate ways to approach sensitive issues. Interviewers must understand **why the research is important**, and why participants need to answer as many of the questions as possible. If the interviewer does not understand the purpose of the research, he or she may be tempted to skip questions or answer on behalf of the interview subjects.

2. The Project Coordinator requires adequate lead time to work with the interviewers, to **develop trusting relationships** with them and to **build team effectiveness** if more than one interviewer is involved. The interviewers also need time to become familiar and comfortable with the questionnaire and the interview process, and to surface any issues, whether about the interview process or about their own **attitudes and beliefs about disability**, that might cause them personal discomfort or prompt a negative response. Some interviewers may benefit from several preparatory sessions with the Project Coordinator to develop the personal clarity and confidence required to conduct successful interviews.
3. It will be helpful for the interviewers to participate in **refining the questionnaire** with the community interest group and/or Steering Committee families before beginning community interviews. This may take the form of doing a **practice interview** with one of these families. After a "trial interview" is held with the family, the interviewers should have an opportunity to **discuss the experience** with the Project Coordinator and the family, and to point out any awkwardness or flaws in the questionnaire or interview procedure.
4. Interviewers should be aware that some families might attempt to cooperate by answering what they think the interviewer wants to hear, rather than from their own experience. The interviewer needs to be able to **assess whether he or she has established a sufficiently trusting relationship** with the family for them to feel comfortable in giving honest disclosures. In communities where the issue of stigma around disability is present, it may help if the interviewer offers repeated **reassurances of confidentiality** and affirms that there are no right or wrong answers.
5. The ideal situation is to have the same researcher or research group conduct all the interviews in your community. If this is not possible, be sure to take the time to **thoroughly orient** the next group of "mid-stream" researchers, or the research results may be inconsistent or incomplete.

2. What are some of the issues around disability?

3. Interviewers should assist in refining the questionnaire

4. Confidentiality must be ensured

5. Researchers should be thoroughly oriented

# Preparation of Interviewers

1. Hold interviewers' discussion groups to talk about disability issues.

2. Prepare interviewers by considering strategies to overcome challenging situations.

1. Before interviewers begin meeting with families, **organize an interviewers' discussion group or forum** where interviewers have the opportunity to talk about disability issues in a safe and confidential environment.

Discuss the following questions:

- What is the prevalent attitude toward disability in your community?
- How were children with disabilities thought of and treated when you were a child? in your country of origin?
- What are your own personal responses to disability now?
- How do you feel about talking about disability issues with families? interviewing someone with a disability?
- What are your emotional reactions to the interview questions?
- What ideas do you have for approaching families in culturally respectful ways without avoiding a discussion of the realities of disability in the lives of their children and other family members?

2. Most or all of your interviewers may have no previous experience conducting research interviews. Conducting interviews may be seen as a potentially intrusive activity that has no parallel in the community's traditional culture. It is therefore important to **prepare the interviewers to deal with challenging situations**, and to consider in advance **strategies that can assist them to overcome initial difficulties**. For example, if interviewers are not prepared in advance to deal positively with the potential stigma that may be associated with disability issues in their community, the initial response of families could be very discouraging. It will be helpful for the Project Coordinator to assist the interviewers to create some mock dramatizations or role plays, based on the information and examples that surface in the interviewers' discussion group. Participating in role plays will help the interviewers to prepare for some of the real life situations and attitudes they might encounter. The following case scenario has been adapted, with permission, from the experience of one of the *Children Enabling Change* interviewers. It can be used in the following way as an educational training tool:

- Introduce **Part One** of the case scenario as an example of some of the challenges faced by an interviewer in a culture where there is a significant amount of stigma attached to children with disabilities.
- Ask the interviewers to reflect on this story and think of potential challenges they might face in their community. What strategies could they use to overcome these difficulties?
- After the interviewers have "brainstormed" possible challenges and strategies, share **Part Two** of the scenario with them to supplement their own ideas and show them how Lien dealt with her challenges.

### Lien's Story: Part One

Lien is a member of the Chinese community of Victoria. She is employed by an inter-cultural agency as a community settlement worker for her community. She has agreed to be one of the research interviewers for the *Children Enabling Change* program.

Lien can see the value of the program for her community, and she wants to help out, yet when she sits down with the questionnaire and realizes "OK, this is what we're going to be asking people," she feels blocked. She discovers she has difficulty even reading through the interview questions, because she is experiencing so many conflicting feelings herself around the subject of disability that she has never really confronted before. In the Chinese community you don't talk about disability.

Lien realizes that as a community settlement worker she needs to deal with disability issues, and she thinks that the *Children Enabling Change* program can make a positive contribution to the lives of many families. However, these taboos and attitudes make her work very difficult. For example, when asked whether information about agencies that offer services for disabled children could be included in prenatal classes at the Inter-Cultural Association of Greater Victoria (ICA), her initial response was "Never, never! It's a prenatal class; you can't even mention the possibility of disability."

When Lien begins to visit families to request their participation in the interviews, she discovers that, not surprisingly, some families do not wish to talk to her. Some families almost demand that she leave their home, a real affront in her culture. In some situations the mother of the child is willing to talk, but the grandmother is present and so the mother cannot discuss disability in the house, as her words could bring bad luck to the family. There are many times when Lien feels so discouraged that she wants to quit.



## Lien's Story: Part Two

In spite of the challenges confronting her, Lien does not quit her role as a *Children Enabling Change* research interviewer. Instead, she draws on her strengths as a community settlement worker and her considerable interpersonal skills to find ways to build genuinely caring and supportive relationships with the families she was assigned to interview.

Lien approaches the families with great sensitivity, tact, patience and above all, empathy. She creates a trusting relationship with each family by first coming to visit and by offering assistance with any issues troubling the family. In her role as a community settlement officer, she offers to help the family in any way she can, and demonstrates her warmth and acceptance of family members with disabilities by her actions as well as her speech. She draws on examples of friends, acquaintances, and distant relatives to illustrate her understanding and empathy for each family. She is respectful of the family's schedule and time demands, and helps out with household routines so that the person being interviewed is not unduly inconvenienced. Whenever possible, she acts to support the family and to meet their immediate needs.

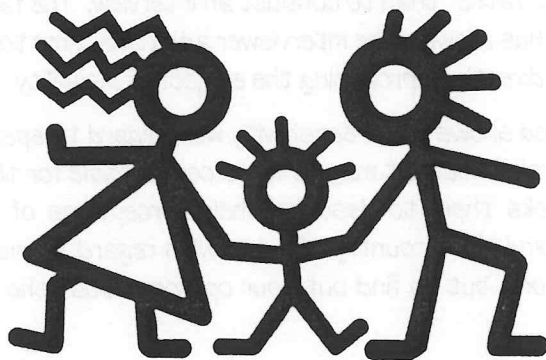
Lien is successful in combining her roles of interviewer and family settlement worker. She introduces many families to the services offered by the ICA, strengthens relationship bonds with the families, and provides much practical assistance. She also helps to design and lead a training workshop on cultural sensitivity issues for health care professionals who serve her community, and takes an active role in analysing the interviews.

Lien is now eager to return to the families she interviewed with the tangible results of the *Children Enabling Change* program, including a brochure translated into Chinese and Vietnamese that explains how to get help for those with permanent difficulties or disabilities and a resource guide listing many different services for children and adults with disabilities. To her this is the most rewarding part of the project, for families are finally getting something tangible that will help them in their day-to-day lives. The head and the body of the dragon finally have their tail.

## Preparation of Interviewers (continued):

3. It is also helpful if the interviewers can be involved in "trial interviews" with initial interest group and/or Steering Committee families, to practice interview skills, test the interview questions for cultural sensitivity, and make any necessary revisions to the questionnaire.
4. Set up a system for interviewers to meet together or one-on-one with the Project Coordinator to discuss any problems or issues that surface in the interviews. If the interview process goes on for several months, a regular monthly progress meeting of all research team members will help to keep communication clear and the process moving, and will help to sustain motivation and mutual support.

The list on the following two pages provides research interviewers with practical suggestions that will help them to conduct effective community interviews. You might wish to photocopy them for distribution to research interviewers in your community. Good luck!



3. Hold "trial interviews."

4. Interviewers should meet regularly to discuss problems or issues.

We are grateful to all who have acted as community liaison officers and interviewers for the Children Enabling Change project. They have contributed the list of practical suggestions that appears on the following two pages to assist you to conduct effective community participation research.



## Suggestions from *Children Enabling Change* Research Interviewers

1. It is better to make family contacts through the community rather than through an institution such as a university or hospital. Requests to participate in research will be much more readily accepted if the referral comes from someone the family knows and trusts.
2. The more links you make with community, the more accurate the information will be.
3. Affiliation with a service organization such as the Inter-Cultural Association of Greater Victoria (ICA) can serve as a useful bridge builder. For example, the interviewer can explain what he/she does at ICA, and that ICA offers services helpful to the family. The experience of immediate assistance, rather than having to wait for the long-term benefits of the research, may encourage the family's participation in the interview process.
4. Do what you can to help the family with disability needs — for example, you may be able to assist with setting up appropriate referrals. Win trust and respect by taking action on behalf of the family and by demonstrating genuine caring and support.
5. Whenever possible, interviewers should try to follow accepted cultural exchanges such as bringing a gift to the family (food, flowers, small gift for child — whatever is culturally appropriate).
6. In cultures where stigma is associated with disability, it may be more acceptable to initially ask to come to "visit" rather than to conduct an interview. The family may be less likely to refuse a visit, thus allowing the interviewer additional time to establish a positive relationship before directly approaching the subject of disability.
7. If the family being interviewed shows some sensitivity with regard to speaking about disability within their cultural context, it may be more comfortable for the family to speak if the interviewer asks them to describe their perceptions of differences between Canadian culture and their country of origin with regard to disability: "I'm not here to ask you questions, but to find out your opinions about the differences between the two cultures."
8. The interviewer must know the first language of the family being interviewed. This is also vital in the broader role of acting as a liaison in the community and making connections to other families. Make sure the questions are simple and easy to communicate in the language of the family.
9. If the person interviewed has some kind of difficulty with speech, have someone else from the family there to clarify responses.
10. Use psychology skills. Put the family at ease. Never rush or look at your watch. Reinforce that the family is contributing important information and supporting the growth of their community.



11. One interviewer trained her husband to do interviews in certain situations — for example, where she felt it would be inappropriate for a woman to ask certain questions of the father.
12. It is important to phrase questions in a way that is sensitive to the culture, and to acknowledge with gratitude the time the family spends in the interview process. If the interviewer feels the questions aren't worded in a culturally appropriate manner, it is important to refine the questions with the research team before beginning the interviews.
13. In a culture where there is much stigma associated with disability, the interviewer must spend considerable time building trust by demonstrating empathy and understanding. For example, holding the child who has a disability may be an effective way for an interviewer to visibly affirm his/her acceptance of that child and to show he/she does not judge the family.
14. It is important to be genuinely respectful, culturally sensitive, and supportive of the family and its needs. For example, the interviewer must be careful to help rather than burden the family, and be sensitive to the time involved in the interview process. Perhaps the interviewer can walk to school with a mother who needs to pick up her child, offer to clean vegetables for lunch etc. These actions will help to build trust and acceptance, and to make it clear that the interviewer is there to help the family and to listen to all their concerns, not merely to gather answers to the interview questions. Remember that building trust can take a lot of extra time.
15. Sometimes you may need to talk around an issue. Be sensitive to situations when you must not be too direct.
16. Make sure the person being interviewed is aware that he/she is under no obligation to contribute information and that the conversation can be broken off at any time.
17. Ensure confidentiality.



# Section B:

## Interview Groups

This section outlines three different community groups who could participate as informants in Step 4 interviews. The first two groups are required for this project, while the third group is optional, depending on services and other resources available to your community.

### 1. Interview families with children with disabilities

#### 1. Interview families that include children or other family members with disabilities

Interviewing families with children or other family members with disabilities is mandatory for a disability-related *Children Enabling Change* project. The purpose of interviewing this group is to:

- assess families' specific disability-related needs;
- determine families' knowledge of existing rehabilitation services;
- identify the barriers preventing families from obtaining satisfactory treatment;
- examine families' attitudes and beliefs about disability;
- examine perceived community support for disability; and
- determine families' current health seeking behaviours.

### 2. Interview community members

#### 2. Interview community members

Interviewing community members is mandatory for a disability-related *Children Enabling Change* project. The purpose of interviewing this group is to:

- determine prevalent community attitudes towards persons with a disability;
- identify beliefs about disability causation and consequences; and

- assess current community knowledge about treatment, prevention, and availability of resources for people with disability.

### 3. Interview health care professionals working in the community

Interviewing health care professionals working in the community is optional for a disability-related *Children Enabling Change* project. However, it is important to conduct these interviews if you want to address some of the health care professionals' issues about providing care. Information learned from the interviews can also help to make educational programs designed for the health care professionals (see Step 6) more meaningful. If you decide not to interview health care professionals, you should have or make a contact in the health care institution to get a sense of the professionals' issues.

The purpose of interviewing this group is to:

- examine the professionals' perceptions of patients' health-seeking behaviour; and
- determine barriers to providing adequate services.

### 3. Interview health care professionals in the community

3. Interview health care

professionals working in the community

3. Interview

health care  
professionals  
in the  
community

Interviews were conducted with health care professionals working in the community. The interviews were semi-structured and lasted approximately 30 minutes. The topics discussed included the role of health care professionals in the community, the challenges they face, and the resources available to them. The interviews were conducted in a confidential and comfortable setting. The data collected from the interviews was used to inform the development of the health care program.

4. Interview community members

The interviews were conducted with community members who were identified through a snowball sampling method. The interviews were semi-structured and lasted approximately 30 minutes. The topics discussed included the community's needs, the barriers to accessing health care, and the community's views on the proposed health care program. The interviews were conducted in a confidential and comfortable setting. The data collected from the interviews was used to inform the development of the health care program.

# Community Participation Research: A Basic Primer

The intent of this primer is to help you understand what community participation research involves, how it is conducted, and why it is useful. The primer provides a framework for conducting the research that will ensure your *Children Enabling Change* program meets the needs of children with disabilities and their families within your community.

## Why is community participation research necessary?

- **Needs Assessment:** Community participation research will help your community identify its specific needs. This will save time and energy in the long term by ensuring that the program your community undertakes meets its specific needs in a culturally appropriate manner.
- **Strengthening Community Partnerships:** Community participation research directly involves your community — children with disabilities, their families, health service professionals, and other community members — in identifying its *Children Enabling Change* program needs, and in working together to meet those needs in culturally appropriate ways. The research is conducted by community-based interviewers (described in Steps 3 and 4) and is designed to support needs identified by community members. Thus, the research stimulates community participation and strengthens working partnerships within your community.
- **Input to Education Programs:** The research results provide important information that will be used in the design and delivery of education programs (Step 6). These programs serve not only to increase community awareness of disability issues and to decrease any stigma associated with disability, but also to educate health professionals

## Community Participation Research is necessary for:

- ✓ Assessing needs;
- ✓ Strengthening community partnerships; and
- ✓ Providing input to education programs.



about the culturally specific disability issues facing your community and the ways to approach these issues in appropriate and sensitive ways.

Four key community participation research questions are explored in the following pages:

1. **Information:** What information do you need, and how will you collect it?
2. **Interviews:** What process is needed to conduct research interviews?
3. **Participants:** Which community members will become your community research interviewers? Who will be interviewed?
4. **Analysis:** How do you analyse the information collected, and use it to benefit your community?

## 1. INFORMATION

**A.** Gather new information and clarify existing information.

**B.** How will information be collected in a culturally sensitive manner?

### 1. INFORMATION: What do you need, and how will you collect it?

- A. This is an opportunity to gather new information and to clarify the information you already have: what you know about the disability needs of your community, how the community is dealing with disability issues, and how families are coping in caring for a person with a disability. The families participating in the community interest group and/or Steering Committee can play a key role here in identifying existing community strengths and support systems, as well as problem issues and barriers in accessing health care for children and other family members with disabilities.
- B. You will need to decide how your research interviewers are going to go about collecting information in a culturally sensitive manner. Are you going to conduct face-to-face interviews? individual or group interviews? send out a questionnaire? go out and observe people's behaviour?

The research procedure we found most useful in this step of the initial *Children Enabling Change* program was the *face-to-face interview*, in both individual and group formats. When interviewers are drawn from community support agencies, the interview process can help to build and strengthen trusting relationships between the families of children with disabilities and the agency.

C. Sending out **questionnaires** can be a useful procedure if there are a great many people from whom you need to gather information and you don't have the time or resources to interview them face-to-face. However, because of the community development focus of this program, and because the questionnaire return rate may be very low, we highly recommend face-to-face interviews whenever possible.

D. This primer includes an **Interview Questionnaire** (page 6) which we recommend for your research interviews, and which was distilled from a list of over 250 questions piloted in the initial *Children Enabling Change* interview process. This simplified list of seven groups of questions represents what the research teams found to be the most useful information-gathering tools for community development. These questions, and the information they helped gather, served as the basis for both the educational brochure and resource guide described later in this manual.

E. The questionnaire includes two different types of research questions:

- **"Open-ended" questions.** These allow people to provide general responses that may include many different types of information. Interview question 5 is an example of an open-ended question.
- **"Closed-end" questions.** These are questions that are answered with either "Yes" or "No", or that provide a choice of response from a scale (for example a scale of 1 through 5 where 1 indicates "strongly agree" and 5 indicates "strongly disagree"). Closed-ended questions are useful if you wish to measure community response to specific issues of concern. Interview question 3 is an example of a closed-ended question.

F. You may add to or otherwise adapt the questionnaire included in this manual to make it more appropriate for your community. Remember, however, that you want your final questionnaire to be fairly brief — a rough guideline is to keep the total time for an interview to an hour or less. Make sure that all interview questions are fairly simple and straightforward, phrased in language that is easy to follow, and that they are relevant to the needs of your community.

C. Questionnaires are beneficial for gathering information from a great many people

D. Sample questionnaire

E. Two different types of research questions

F. Please add to or adapt the sample questionnaire



## G. Translating interview questions

H. Check the wording of translated questions. Be careful as to how the word "disability" translates in other languages. The English terminology which may translate better is "permanent difficulty."

- G. If the interviewers wish to conduct interviews in their first language, it is important to have one person **translate** the interview questions, and a **different person re-translate the translated questions** back into English. This double translation should take place before you begin the community interview process. It will help to ensure that the intent of the interview questions have not been altered in the first translation because of subtle language differences.
- H. It is very important that **someone sensitive to disability issues checks the wording of translated questions**, to ensure that the questionnaire is free of potentially stigmatizing language or any other unintentionally insensitive phrasing that could give offense. If your community interest group (Step 1) or Steering Committee (Step 3) includes a few families who have children with disabilities, it would be most helpful to fine-tune your translated questionnaire with their assistance before beginning community interviews. This provides an important opportunity to test the translated questions to make sure they are easily understandable, and that they are phrased in a culturally acceptable manner. Be sure to ask family members "How would you feel if someone asked you this question?" Their feedback must be treated with great sensitivity, as there may be an issue of stigma associated with disability in certain cultural groups. It is crucial, therefore, that the family members interviewed at this preparatory stage have sufficient trust in the interviewer and are comfortable enough with disability issues to offer a thorough critique of the questions. Without this frank response, interviewers might not realize that the wording of an interview question is unintentionally offensive to families who have children with disabilities, and could prompt these families to decline any future participation in the program. This family review process will provide you with the opportunity to rephrase those questions that are inappropriate, and to create a more culturally suitable questionnaire. If extensive revisions are required, be sure to repeat the double-translation process and to check with the community interest group families once again for approval of the revised questionnaire before beginning the community interview phase.



1. Because of the time constraints of most Canadian health care institutions, it would likely be difficult for volunteer interviewers to conduct face-to-face interviews at a hospital or other health care institutions. An optional mail-out questionnaire for health care professionals, consisting of open-ended questions on the key interview subjects (for example, "What do you think are the major worries for clients from this community?"), is therefore included in this primer (page 11) as an optional research tool. It is helpful to include a brief project overview and description of the potential benefits with the mail-out questionnaire (see sample). It would also be helpful if the Project Coordinator could enlist the support of a health care liaison person from the institution in promoting the project. This in-house support will encourage a greater response rate to the questionnaire.

1. Sample  
questionnaire for  
health care  
professionals

### Differentiating between Focus Groups and One-on-One Interviews

In the initial *Children Enabling Change* project, a two-step process was used with the interviews:

1. In **Step 1**, needs were identified using **focus group interviews**. In this process a group of 8-10 family care providers and people with disabilities were brought together to discuss their needs, concerns and hopes relating to disability. The Project Coordinator facilitated the discussion by asking key questions and a recorder transcribed the discussions. The purpose was to gather information on these key issues in a semi-structured way, whereby participants focused on a topic introduced by the Project Coordinator who then encouraged the discussion to develop in a process that was comfortable to the group. Due to the group dynamic involved in focus groups, this method is very useful for gathering general information on needs, as well as cultural and community information.
2. In **Step 4**, **one-on-one interviews** were carried out. In this step, trained community-based research interviewers went to the homes of families and other community members, and carried out face-to-face interviews in a setting that supported family and community members to feel more comfortable discussing personal issues. One-on-one interviews are often useful for collecting information relating to informants' personal attitudes, beliefs, or values.

✓ **P.S.:** Some useful readings...

Lonner, W. & Berry, J. (1986). *Field methods in cross-cultural psychology*. London: Sage Publications.

Morette, D., Sullivan, T., & DeJong, C. (1994). *Applied social research: tool for the human services*. Chicago: Harcourt & Brace Publishers.

Morgan, D. L. (1988). *Focus groups as qualitative research*. London: Sage Publications.

## Children Enabling Change Interview Questionnaire

### 1. Demographics (general background information)

Name or number of participant

Ethnicity

Age

Disability or type of difficulty experienced

Number of family members in household

Primary care giver of the person having ongoing difficulty (disability)

### 2. Health Sectors Used

In the past have you sought help from the following:

- a) Hospital
- b) Family Doctor
- c) Physiotherapist
- d) Occupational Therapist
- e) Speech Language Pathologist
- f) Psychologist or Social Worker
- g) Community Nurse
- h) Traditional Doctor or traditional medicine
- i) family remedies
- j) Other (Child and Youth Care Worker, etc.)

Which of these were you most satisfied with?

Which of these would you use again?

Are there any of these that you would NOT SEEK HELP FROM AGAIN? If so why?

Do you know of services available to you AND HOW TO ACCESS THEM? If yes, please list some examples.

Do you have any suggestions that might help to make any of these services more helpful to you? Please state which one and how it could be improved.

### 3. Possible Barriers to Health Care

Do any of the following issues make getting the help you need difficult? Please select one of the five numbered options for each question with 5 being a serious problem and 1 not being a problem at all.

For example...

If language was a very big problem and you couldn't understand anything that the health care professionals were trying to say or make them understand what you wanted to say, you would mark 5.

Or, if you understood most of the discussions and could make yourself understood, but still felt a little uncomfortable you might mark 2.

	not a problem			serious problem	
Language	1	2	3	4	5
Transportation	1	2	3	4	5
Time off work	1	2	3	4	5
Child care	1	2	3	4	5
Different cultural beliefs about illness and disability	1	2	3	4	5
Knowledge about services	1	2	3	4	5
Other _____	1	2	3	4	5

#### 4. Knowledge of Community Services

Are you aware of any services that are available for people with disabilities or permanent difficulties in the larger community, such as....

Respite?

Community living?

Other NGO's and government services? (please specify)

#### 5. Community Support for People With Disabilities and Family Support for People With Disabilities

Are there any services within your cultural community that help people with disabilities? If yes, what are they?

Do people within your community go out of their way to include or otherwise support people with difficulties or disabilities or do they tend to ignore them? If yes, how are they supported?

Does this differ between adults and children? If yes, how?

Does this differ with someone who has acquired a disability through an accident or old age vs. someone who was born with a disability? If yes, how?

Within your family, do you feel that there is a lot of help, understanding and support or are there negative feelings towards you or your child with a disability? Please explain.

## 6. Cultural Attitudes Towards Disability

What is perceived to be a disability?

What would be considered a disability in your country of origin?

Is that the same as it is here in Canada?

Are people with specific disabilities or permanent difficulties accepted as part of your community? Please explain which disabilities and why they are accepted.

Are there specific disabilities or permanent difficulties that are NOT accepted in your community? Please explain which disabilities and why they are NOT accepted.

Would it be OK for someone with a disability to have a regular job?

Would it be OK for your son or daughter to marry someone with a disability?

Normally is it OK to talk about disability? Please elaborate and give examples.

Do you feel that disability is preventable or curable? Please explain.



## 7. Other Community Resources

Please list any other resources within your cultural community such as cultural organizations, schools, clubs or religious bodies.

How do these resources support people with disabilities and/or families with a child with a disability?

If there is stigma around this issue, do you think that any of these organizations might be of help in addressing this stigma?

## 8. Is there any other information about disability that you feel is important to know? Please elaborate.

## 9. Do you have any suggestions on how to address some of the issues mentioned above?

## Sample Mail-out Questionnaire to Health Care Professionals

### Cover Letter

Dear Health Care Professionals,

A research study is being carried out in Victoria, B.C., by the Intercultural Association of Greater Victoria, School of Child and Youth Care, University of Victoria, Queen Alexandra Centre for Children's Health, and families from multi-cultural communities. The purpose of this research is to create more culturally sensitive health care for people who have a permanent difficulty or a disability. This includes people who experience difficulties with learning, seeing, hearing, moving, as well as anyone who feels that they are being stigmatized due to some feature or behaviour that is different from others.

The goals of the research are:

1. to help health care professionals provide better service to children and adults with a disability or permanent difficulty that are from different cultural communities.
2. to help these cultural communities better understand services that are available for individuals and families with a disability or permanent difficulty and to assist them to successfully access these services by overcoming existing barriers.

We would appreciate it if you could take 20 minutes of your time to fill out a brief questionnaire to assist us with this study. The questions look at your perceptions and experiences working with various cultural minorities with disabilities.

You are under no obligation to participate in this questionnaire and you may stop at any time. All responses are confidential, cannot be traced back to the respondent, and will not affect employment status in any way.

Your input and participation are greatly appreciated and valued, and will contribute to better servicing people with disabilities from cultural communities.

If there are any questions, please contact the "Children Enabling Change" Project Coordinator at \_\_\_\_-\_\_\_\_.

Please return the questionnaire in the self addressed envelope as soon as possible. Thank you for your participation.

## Children Enabling Change Health Care Professional Questionnaire

### CONFIDENTIAL

1. Have you had any experience working with families from different cultural backgrounds that have a family member with a disability? Please specify cultural group.

If not, please stop here and return the questionnaire.

If answering for more than one cultural group, please specify which group when answering questions 2-16.

2. Have you been satisfied with the service that you were able to provide for these families? Please explain.
3. Describe any positive or difficult experiences that you encountered when working with people with disabilities and their families from these cultural groups.
4. Did you participate in any training to assist you in working with different cultural groups?

If yes, was this helpful?

If no, would you like more information?

5. What type of information would be helpful?



6. Do you feel that clients from these cultural groups are making full use of the services offered at this institution?

If not, please circle if you think that this is because of:

- a) a lack of awareness of services
- b) don't speak English
- c) cultural beliefs
- d) use of traditional medicine
- e) other

Please explain.

7. Do you feel that clients from these cultural groups are making full use of the support services offered within the community (i.e. respite, financial support)?

If not, please circle what you think may be the cause:

- a) a lack of awareness of services
- b) don't speak English
- c) cultural beliefs
- d) use of traditional medicine
- e) other (i.e. reliance on family)

Please explain.

8. Do you feel that clients from these cultural groups follow through with programs or recommendations?

If not, please explain why you think that this is happening.

9. Is language a barrier to providing adequate care?

If so would access to interpreters be helpful?



10. What skills and knowledge are needed to be an effective interpreter?

11. Are you aware of any resources within these cultural communities? Please list.

To assist professionals?

To assist families?

12. Are you aware of any other resources such as:

- a) traditional healers or medicine
- b) cultural traditions
- c) extended family
- d) elders
- e) support groups?

Please explain what they are and if you refer to or use any when delivering services.

13. How do you feel disability is perceived within the family?

Within the cultural group?

14. Are people with disabilities accepted in this community?

15. Do people feel that they can prevent, cure or improve disabilities?

16. Is there any other information that you would like to share about working with people with disabilities and their families from multi-cultural communities that might be useful?

**THANK YOU AGAIN FOR YOUR PARTICIPATION!**

## 2. INTERVIEWS: What are the steps involved in conducting research interviews?

Community participation research interviews follow several steps:

- A. **Introduction:** The typical format for the research interview is to begin with an introduction of the project, the research focus and intent, the interviewer, and the organization or research group represented. It will be useful to prepare a standard written version of this introduction prior to the interview, particularly if research is being conducted by more than one interviewer. It is certainly not necessary for the interviewer to read out this written introduction, but it should be available to hand out to participants if requested (translated if required). It will provide useful reference material for the interviewer and serve as a reminder to cover all important points.
- B. **Informed Consent:** The next step is for the interviewer to review and reach agreement with the research informant on the ethics of the interview process itself. This step is referred to as reaching "informed consent." It means that the person being interviewed understands that they have the right to refuse to answer any question and to end the interview at any time. The person being interviewed also needs to know how to contact the supervisor of the research program if for any reason they have issues or problems with the interview that they wish to resolve. The interviewer and informant should review and agree to abide by confidentiality practices that are acceptable to the informant: for example, the informant's name should be kept confidential, with responses identified by number rather than by name. A record of the person's name and address may be kept separately to allow future information to be sent.

## 2. INTERVIEWS

Please note that specific information on training community researchers can be found in Step 4.

A. Introduce the project, research focus, intent, the interviewer, and the organization

B. Review the ethics of the research process

C. Gather  
demographic  
information

D. Sample questionnaire

E. Include statement  
describing how research  
will be used

C. **Demographic Information:** When you begin the interview, it is often useful to gather some demographic information. Demographic questions are provided at the beginning of the sample questionnaire provided on page 6 of this Research Primer. They include information such as the interview participant's identifying number, gender, age, ethnicity, type of disability (if appropriate), country of origin, length of time living in Canada, languages spoken.

D. **Interview Questionnaire:** See sample included on page 6 of this Research Primer.

1. **Summative Statement:** It is useful to include a statement at the end of the questionnaire describing how the research is going to be used, and to give the respondent a written description of how to contact the research team or sponsoring agency for further information and feedback, as well as possible future involvement in the project.

### 3. PARTICIPANTS

#### 3. Participants: Who will be your community participation research interviewers? Who will be interviewed?

The third task in community participation research is to decide who will participate. By identifying the specific **community-based research interviewers, children and families, interested community members** (for the purpose of this primer, interested community members are considered to be people in the community who do not have a family member with a disability), and **health care professionals** who will benefit from community development and support around issues of disability, you begin the process of building relationships with each of these groups. This is a useful first step in strengthening effective community support partnerships.

#### Selecting Research Interviewers

A. The Steering  
Committee should select  
appropriate research  
interviewers

A. The selection of appropriate **research interviewers** is crucial to the success of the *Children Enabling Change* program. If possible, the selection should be made by members of the Steering Committee (Step 3), perhaps a subgroup made up of key community members including

families and support agency representatives, chaired by the Project Coordinator.

- B. It is important that the research interviewers selected are respected and trusted members of the community. If your community has a cultural centre or community support agency (particularly one with established links to children with disabilities and their families), staff members from this organization would be likely candidates. For example, staff members of Victoria's Inter-Cultural Association of Greater Victoria (ICA) played an invaluable role as community liaison and research interviewers throughout all steps of the Victoria program.
- C. If your community does not have an organization such as ICA, the project focus group can recommend people with community development experience and appropriate language skills. Strong interpersonal or counselling skills, combined with tact, patience and cultural sensitivity will help interviewers to build trust and clear communication with research participants. Ideally, the interviewers will have some prior background in research methodology; however, the Project Coordinator can assist a person with strong community development skills to learn the required basic research skills prior to conducting interviews. Suggestions for training research interviewers are outlined in Step 4, Section A.

### Selecting Families

- A. Once interviewers have been selected, the Project Coordinator will meet with the members of the Steering Committee to decide how to select families to participate in the interviews.
- B. "Sampling technique" is the research term describing how families are selected to be interviewed. Because of the potentially sensitive nature of the interviews, particularly in cultural communities where disability is associated with stigma of some sort, we have found the most successful technique is a "sample of convenience." This means that the community focus group identifies families with children with disabilities who have some type of relationship or connection to organizations sponsoring the *Children Enabling Change* program. Families connected to local community clubs, schools, or other places where there is generally a trusting

### B. Research

interviewers should be respected and trusted community members

### C. Research

interviewers can build trust with participants

A. Decide how to select families

B. Selecting families using a sampling technique



**C.** Selecting families  
using hospital records

**D.** Selecting families  
through referrals

**E.** See Step 4,  
Section A for more  
suggestions

**A.** Gathering  
feedback from  
community members

**B.** Interviewing  
community members

relationship between families and the people working in those institutions, may also be identified as initial contacts.

C. If you are working with a hospital, you may be able to access hospital records, but again, caution needs to be exercised: not only must you maintain confidentiality in accordance with hospital policy, you must also make sure that the families selected in this way understand the purpose of the research and are comfortable with participating, before you attempt an interview.

D. The patience, tact, and genuine warmth and caring of the interviewers play a vital role in eliciting recommendations from families who initially agree to be interviewed. Interviewers in the first programs found that, once the first few families understood the purpose for the research and a trusting relationship with the interviewer had been developed, they were willing to discuss the program with others, and gradually "word-of mouth" contact was made with many families in the community. This method of family-to-family referral proved to be the most effective way of gaining acceptance in the community.

E. The first *Children Enabling Change* interviewers have contributed many valuable suggestions as to how to conduct interviews in a culturally sensitive manner. These suggestions are listed in Step 4, Section A.

### Selecting Interested Community Members

A. It is often useful to interview people in the community who do not have a family member with a disability. This will help you gauge the degree of understanding and acceptance of disability issues within the cultural community.

B. Interviewing these people also helps raise awareness on disability issues and helps prepare the community for community education programs that may result from the research.

## Selecting Community Health Service Professionals (optional)

- A. If there is some way to gather feedback from health care professionals that work in your community, it could provide useful information in the design and delivery of Step 6 education programs.
- B. A local community service agency may be able to liaise with health care professionals responsible for disability services in your community. If your Steering Committee includes one or more health service professionals, ask whether they could act as a liaison for this portion of the research.
- C. The selection of professionals can be done randomly. For example, send a questionnaire to every fourth person on a list of all the agencies with health care professionals. You could also meet with a few key professionals and hold a focus group to discuss the issues.

A. Gathering feedback from health care professionals is useful

B. Select a liaison

C. Choosing professionals through random selection

## 4. ANALYSIS: How do you analyse the information collected, and use it to benefit your community?

When it comes time to analyse the information collected in the interviews, it is helpful to refer back to the two types of interview questions, "open-ended" and "closed-ended," described earlier in the Information section of this primer (page 3). The responses to these two types of questions provide examples of the two basic types of research analysis, referred to as "qualitative" and "quantitative" analysis. The answers given to open-ended interview questions are examples of qualitative research, where the answers are in sentence or "text" form. The answers to closed-ended interview questions are examples of quantitative research, where the answers are in number form or are easily translated into numbers (for example, out of 25 interviews, 20 people or 80% answered yes to a particular question).

Both qualitative and quantitative research provide valuable information for community participation research. Qualitative information is useful to highlight important research themes, and to find out more about key issues, particularly those involving values and beliefs. Quantitative information is more useful in pinpointing the degree of severity or impact of issues in

## 4. ANALYSIS

Quantitative and qualitative analysis



showing which of these themes are the "big issues" for the community at the time.

Qualitative results and analysis

## Qualitative Results and Analysis

Each type of information is analysed in a different way. Qualitative research is analysed through a process referred to as a "content analysis" or "thematic analysis." The person, or group of persons, doing the analysis focuses on themes that were initially identified through the focus group family interviews or community discussions. For example, if the theme of language as a barrier had surfaced in the initial interviews, the person doing the analysis looks through all the interviews and gathers all the references to language. This information is then used to discuss the issue of language in the research results. (This same information could also be approached as quantitative research by counting the number of times that language was described as a barrier in the interviews.)

Qualitative research highlights themes

Qualitative research is often very helpful in bringing to light new themes. The person doing the analysis can look through the interviews for repetition of themes in several different interviews, whether or not they were identified in the initial interview process. These themes can then be clustered together, or examined to see how they might relate to each other. (This involves analysing correlations between factors, a more complex process that you can learn more about from a basic research text such as Patton, M. Q. (1990). *Qualitative Evaluation and Research Methods*, Second Edition. London: Sage Publications.)

Analyse qualitative data using a team approach with interviewers

Qualitative data should be analysed using a team approach with the interviewers present. This is particularly vital if the information needs to be translated, but the interviewers also play a crucial role in cross-referencing research results with their own experience, impressions, and perceptions. Post-interview conversations between analysts and interviewers can highlight significant qualitative themes. In the process of conducting interviews, major issues may surface that are not reflected in the interviews themselves. — for example, repeated requests for a community support group, made by families after the interview concluded would otherwise go unrecorded.

## Quantitative Results and Analysis

Quantitative research analysis involves a number of different strategies. The answers to closed-ended interview questions, whether yes/no or a range of responses on a numbered scale, provide answers that translate into numbers. The most basic method, therefore, is to analyse the frequency of a response — for example, how many times did people answer "yes" to a particular question.

Quantitative results  
and analysis:  
strategies

The answers to yes/no questions can be easily translated into frequencies (numbers) or percentages. For example, if 25 people (frequency) are asked whether language presents a barrier to accessing appropriate health care for their children with disabilities, and 20 respond with "yes," the response can be stated as follows: "80% (20/25) (n=25) of the people interviewed agreed that language presents a barrier to accessing appropriate health care for their children."

Translating yes/no  
answers into  
frequencies

Mean scores are a useful quantitative measure for scales. For example, if 25 people were asked to respond to the same question on a scale of 1 through 5, with an answer of 1 indicating strong agreement that language was a problem in accessing appropriate health care, and an answer of 5 indicating strong disagreement, the results can be averaged to determine the degree of severity of the problem. For example, you could say that "Out of 25 responses, the average response was 1.8, indicating that language is perceived as a relatively severe barrier to accessing services."

Average scores



## Qualitative Results and Analysis

Quantitative research involves a number of different strategies. The purpose of this study was to explore the experiences of a group of people who had been exposed to a natural disaster. The study was designed to explore the experiences of a group of people who had been exposed to a natural disaster. The study was designed to explore the experiences of a group of people who had been exposed to a natural disaster.

Qualitative  
Research  
Methods

The purpose of this study was to explore the experiences of a group of people who had been exposed to a natural disaster. The study was designed to explore the experiences of a group of people who had been exposed to a natural disaster. The study was designed to explore the experiences of a group of people who had been exposed to a natural disaster.

Qualitative  
Research  
Methods

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# Step 5:

## Consult with the larger community

In this step of the *Children Enabling Change* program, the research results of Step 4 will be reviewed by your Steering Committee. The committee will be asked to give feedback on proposed educational programs, including the approach best suited to your community, and to identify information essential to include in these programs.

This step serves to promote a high level of community involvement and guidance in shaping the educational materials produced in Step 6. Community involvement helps to ensure that the proposed educational materials will:

- be presented in a culturally appropriate form
- meet the expressed needs of families with children with a disability in a culturally sensitive manner
- raise the understanding and acceptance of disability within the community
- build on existing community strengths and
- create sustainable relationships between health care providers and community members.



Step 5 is an  
evaluation  
step

Steering Committee  
reviews research  
results

Promote community  
involvement and obtain  
guidance in forming the  
educational materials  
for Step 6

# How to Climb Step 5

These practical pointers, taken from successful *Children Enabling Change* programs, will assist you in planning for your own community program.

Your Steering Committee may decide to hold a larger "town hall" style community meeting at this time to share the results of the research. You may choose to put an advertisement in your local newspaper, or to invite people to attend the meeting through community organizations and agencies (the Chinese Lions Club, the Inter-Cultural Association of Victoria, and the Bridge Health Clinic, a multi-cultural health clinic at Mount St. Joseph Hospital in Vancouver helped to advertise these meetings or acted as hosts).

In the initial *Children Enabling Change* project, families who participated in the research and key community members received special invitations in the following way. They were first telephoned by a member of the Steering Committee, then sent a written invitation and asked to respond, and then telephoned once again a day or two before the meeting to remind them. Child care was provided at the meeting, and transportation to and from the meeting was offered. Food was provided at the meeting as well. All were important elements in ensuring a strong community turnout.

For those who could not be at the meetings, a liaison person (usually the interviewer) contacted the families who couldn't attend and let them know what was talked about, so they were still included in the process.

To illustrate the process, some of the *Children Enabling Change* results from the Chinese community of Victoria are described on the following page.

## Research Results from the Victoria Chinese Community

Researchers in the Chinese Community interviewed 140 persons. Of these 32 (23%) were family members caring for a child with a disability, 62 (44%) were community members, and 46 (33%) were adults with a disability. Interviews were carried out in these peoples' homes by the interviewer.

Two of the issues identified in community interest groups were addressed in the interviews. These were:

- the degree to which families with a disability were using community resources, and
- issues that prevented people from adequately accessing health care (barriers).

When responding to the degree to which families with a disability were using community resources, only 19 % (n=6) of family care providers for children with disabilities had any knowledge of at least one community support service (i.e. respite, home care, vocational training). The services mentioned most often were the local immigrant settlement agency and the community health department (CRD).

Five point scales (closed questions) were used to measure respondents' perceptions of barriers to accessing services. The two most significant barriers identified were **language**, where the average (mean) scale score for family care givers was 4.2, and **transportation**, where the average (mean) score for transportation was 3.6. (1=low, 5=high)

In open-ended questions on attitudes and beliefs towards children and adults with a disability, community members showed more negative attitudes towards children than towards adults. Content analysis revealed that many of these negative attitudes were associated with feelings of shame and punishment of previous wrongs.

The information from these interviews was later shared with families of children with disabilities, adults with a disability, community members and health professionals. Strategies were then designed to try and reduce these barriers and create a more welcoming environment for children with disabilities in the community.

## Research Results from the Victoria Chinese Community

Participants in the Chinese Community Interviewed 140 persons. Of these 55 (39%) were women members living in a home with a telephone and 85 (61%) were community members and 45 (32%) were adults with a telephone. Interviews were carried out in three phases: first by the interviewer.

Two of the issues identified in community interviews groups were addressed in the Chinese Interview.

- The degree to which families with a telephone were using community resources and
- Second, that interviewers from an area of community resources (family).

After responding to the question to what extent with a telephone were using community resources only, 57 (41%) of family care and care for children with disabilities had any knowledge of at least one community support service (i.e. health home care, vocational training). The service mentioned most often was the local transport service (23%) and a community health department (20%).

In a second section (closed questions) were asked to measure respondents' perceptions of barriers to accessing services. The two most significant barriers mentioned were language where the average (mean) score for family care was 4.5 and transportation where the average (mean) score for transportation was 3.6 (1=low).

A third section (open questions) asked respondents to describe children and adults with a disability. Community members showed more positive attitudes towards children than towards adults. Community members showed more positive attitudes towards children than towards adults. Community members showed more positive attitudes towards children than towards adults. Community members showed more positive attitudes towards children than towards adults.

The information from these interviews was later shared with families of children with disabilities. A second community interview was carried out with families and health professionals. Interviewers were then designed to try and reduce these barriers and create a more supportive environment for children with disabilities in the community.



# Step 6:

## Devise and deliver education programs for the community and health care professionals



Step 6 is an  
action step

Step 6 has two phases:

- Phase 1: **Community Education Program:** An education program is designed for and delivered to the **community** in a culturally appropriate manner, and
- Phase 2: **Health Care Professionals Education Program:** An education program is devised for and delivered to **health care professionals**.



# How to Climb Step 6

## Phase 1:

### Community Education Program

These practical pointers, taken from successful *Children Enabling Change* programs will assist you in planning for your own community program.

## Phase 1: Community Education Program

### A. Design the education program for the community

In this phase, the results of the research carried out in Step 4 will be applied to devise an education program for the community.(e.g. workshops, information brochures, alternative education projects such as the use of theatre, puppets, or child to child education).

It is vital that the community be consulted to determine the most appropriate form of educational programs for their community. For example, research with the communities revealed that there was significant lack of information about available resources, and that there were social, cultural and infrastructural barriers that needed to be overcome if children with disabilities in these communities were to enjoy full access to the services available to them.

Program facilitators were continually reminded that a community process such as *Children Enabling Change* requires time and the willingness to work slowly with the community. A flashy or high-profile approach would have been inappropriate for these multi-cultural communities. Time is needed to develop trust and presence in the community through word-of-mouth that the program is truly helpful and seeks to strengthen relationships with existing service agencies within the community.

If the community decides that workshops would be culturally appropriate, they can be designed to address the issues of improving attitudes towards children and other persons with a disability, and to suggest means of reducing existing barriers and integrating these persons into community activities. Information brochures that list resources and services available to families with children with a disability are another possibility. They can be produced and translated into the language most appropriate for the community.

If you decide that a **workshop** is both culturally appropriate and needed in your community, you may wish to contact an educational consultant, and/or identify a community organization to assist in the development of the workshop. Presenters and participants can be drawn from the community organizations involved in the project, from families with a child with a disability, and from the wider community. The workshops should be designed to meet the program objectives that have been identified by the community.

Information brochures  
and printed educational  
materials

If you decide that other educational strategies, such as **developing information brochures or other printed educational materials**, are more appropriate for your community, you might consider establishing a collaborative partnership between educational consultants and your community Steering Committee to develop the materials required.

The initial *Children Enabling Change* program in Victoria had envisioned the delivery of two workshops, one for health care professionals, and one for the community, to address these issues. However, community feedback (primarily from the community interest group and Steering Committee, including several families who had children with disabilities) was that a public workshop would be too high-profile and uncomfortable for most families to attend. They suggested other approaches that maintained family confidentiality, had a long lasting effect, and profiled existing community support services, such as sharing information about disability through agencies, churches, temples, schools, and community-based newspapers.

## **B. Deliver the education program to the community**

Gradually a new community-appropriate strategy evolved, resulting in a workshop for health professionals, plus the publication of an interlinked series of educational resources for the community to meet the need (determined through the research carried out in Step 4) for more information about services available in Victoria. These publications included:

✓ **Information Brochure: "3 Steps to Getting Help  
for those with permanent difficulties or disabilities"**

The brochure provides the "public gateway" to the resources available in Victoria, and acts as an initial link to the other educational resources produced by the *Children Enabling Change* Project. It assists families to understand what the term "disability" means in Canada, and highlights a few key contact agencies and services that provide interpretation and other support services for families who wish to access services for their children or other family members with disabilities. The brochure has been translated into several community languages, including Cantonese, Vietnamese, and Punjabi, and has been distributed to agencies, service groups, churches, temples, schools, and physicians.

✓ **Victoria Resource Guide: "Getting Help  
for those with permanent difficulties or disabilities"**

The resource guide contains listings and brief descriptions of resources available for those with permanent difficulties or disabilities, including medical services, special equipment, schools, housing, travel, and recreation opportunities. The resource guide was specifically targeted at agencies responsible for helping families with children with disabilities.

✓ **Action Plan: "Children Enabling  
Change Overview and Manual"**

This two-part publication includes an **Overview Booklet** that describes the broad intent and purpose of the *Children Enabling Change* program, together with the **Action Manual** you are currently reading. Together they present a detailed "how-to" description of the process of conducting *Children Enabling Change* programs for and with children with disabilities and their families in multi-cultural communities in Canada.

## Phase 2: Health Care Professionals Education Program

### A. Devise an education program for health care professionals working with children with disabilities and their families within the community

Results from the data collected in Step 4 can be used to design a workshop for educating professionals who work with families with children with disabilities in the community. Your community focus team will need to decide the exact format and content of these workshops, based on your community needs. You may decide that the services of an educational consultant are required, or you may be able to draw on the expertise of community service professionals to help plan and deliver the workshop. It is likely that the workshop will examine differences in practitioners' and clients' perceptions of disability, and will suggest strategies for assessing community disability needs, supplying culturally appropriate treatment, and overcoming barriers to providing adequate services. The Workshop Planning Resource, found on page 16 of this Step, will assist you in planning your workshop, and the Reference and Resource list found on page 17 will provide you with more resource material about working with families of different cultures.

The workshop will need to address the needs of the professional health care community. If you are not able to interview professionals in advance (see sample letter and questionnaire in the Community Participation Research Primer), it will be important to liaise with a representative of the health care community who can let the workshop planners know what the main issues are, and help them to ensure that the information covered in the workshop is relevant, practical, and experiential. The workshop should include information on how health care professionals may access additional culturally specific information on the communities they serve. If language barriers are an issue, the workshop may also provide an opportunity to explore possible ongoing provision of interpretation for health care professionals by community support organizations or the training of interpreters in medical issues and terminology.

## Phase 2: Health Care Professionals Education Program.

The workshop for health  
care professionals  
needs to be practical  
and experiential

Our sincere thanks  
to the community  
family members who  
have children with  
disabilities, and who  
gave so generously  
of their  
participation in this  
workshop as well as  
in all other aspects  
of the *Children  
Enabling Change*  
program. Your  
children and your  
community will  
benefit from the  
courage and  
compassion you have  
shared with so many  
others.

## B. Deliver the education program to health care professionals

Workshops can be organized by your Steering Committee, with the assistance of an educational program consultant or other resource people working with your team. You will need to decide on a date, time, and length of the workshop (half-day, full day, or two half days). This will depend largely on your audience and their time availability. Participants can be drawn from health care professionals serving people with disabilities and the community. The workshop can focus on developing strategies for reducing professional barriers to providing culturally sensitive care for children and other family members with disabilities in multi-cultural communities. This will serve to increase health care professionals' understanding of the family's perspective on disability, and to strengthen links between health care services and the community.

This step includes samples of the following materials from the workshop delivered to health care professionals at the Queen Alexandra Centre for Children's Health:

- poster inviting health care professionals to attend the *"Working with Families of Different Cultures" Workshop*, held at the Queen Alexandra Centre for Children's Health in Victoria;
- workshop timeframe and outline;
- workshop handouts.

You may want to adapt these materials to meet the needs of your own workshop participants.

# Working with Families of Different Cultures

Wednesday, May 22, 9:00 - 12:00

Auditorium, Queen Alexandra Centre, 2400  
Arbutus Road, Victoria

This 3 hour practical workshop facilitated by Dr. Philip Cook and Michele Cook, BScPT., draws on research carried out in the Victoria area with different cultural minorities. Share the experiences of families with children with disabilities and persons with disabilities from these various cultural groups. How do they experience the care offered to them? Does the service provided meet their needs medically? Culturally? Emotionally? Hear from community members and families themselves and discover practical ways to better meet the needs of this population.

There is no charge for this workshop, but you must pre-register as space is limited. To register, call Amanda Maier at 721-6825. Ethnic refreshments will be served.





## Sample Workshop Timeframe and Outline

### WORKING WITH FAMILIES OF DIFFERENT CULTURES AN EDUCATIONAL WORKSHOP PRESENTED BY ICA; SCYC, UVIC; and QACCH

#### TIME FRAME

WHEN: MAY 22, 1996

WHERE: Queen Alexandra Centre for Children's Health,  
2400 Arbutus Road — Auditorium

TIME: 9:00 - 12:00

#### OUTLINE

##### Objectives

- I Provide professionals with knowledge, skills and some self awareness to help them work effectively with families from different cultural communities.
- II Improve links to cultural communities and families.
- III Work out strategies for professionals to use to help them work through difficulties that they might be experiencing in working with different cultural communities.

##### Blueprint

- A Describe "Children Enabling Change" project  
Introduce participants and profile ICA & the communities  
Describe key principles (15 min.)

- B Self Awareness exercise
- experience what it might be like to immigrate to another country
  - look at your own expectations, perspectives and biases
  - how do these relate to disability? (30 min.)

- C What is Culture? A look at perceptions! (20 min.)

Coffee Break (15 min.)

- D Summarize experiences of ethnocultural families in Victoria  
Highlight key issues (30 min.)
- E Practice Based Experiences (case studies)
- break into small groups
  - each group choose a scenario from their experience that they found difficult (or one will be provided). As a group, discuss the issues and try to find solutions. Look at the situation from all perspectives (i.e. family, child and practitioner).
  - one cultural resource person and one facilitator will be available for each group. (40 min.)
- F Report back to large group  
Summarize strategies for working through issues (10 min.)
- G Conclusion  
working across differences  
use of available resources  
distribute handouts (5 min.)



# WORKING WITH FAMILIES OF DIFFERENT CULTURES

AN EDUCATIONAL WORKSHOP  
PRESENTED BY

ICA  
(INTER-CULTURAL ASSOCIATION OF GREATER VICTORIA)

SCYC, UVIC  
(SCHOOL OF CHILD AND YOUTH CARE,  
UNIVERSITY OF VICTORIA)

and QACCH  
(QUEEN ALEXANDRA CENTRE FOR CHILDREN'S HEALTH)

MAY 22, 1996

Funded by  
The BC Health Research Foundation

## Sample Workshop Handouts

### WORKING WITH FAMILIES OF DIFFERENT CULTURES SUGGESTED STRATEGIES

One must recognize that each person and family is unique. There are no set "recipes" for working with families of different cultural backgrounds.

**BUT....**

Here are three basic concepts or tools to help you make these interactions significantly more successful.

1.

IMPROVE YOUR **KNOWLEDGE** BASE  
ABOUT CULTURES THAT ARE NEW TO YOU.  
WHAT DO YOU KNOW?

2.

DEVELOP YOUR **SKILLS**  
TO ENSURE  
EFFECTIVE INTERACTIONS  
WITH FAMILIES FROM CULTURES DIFFERENT FROM YOUR OWN.  
DO YOU KNOW THE CORRECT WAYS?

3.

BECOME MORE **SELF AWARE**  
OF YOUR OWN OPINIONS, ATTITUDES  
AND ASSUMPTIONS ABOUT VARIOUS CULTURES.  
ARE THESE ACCURATE?



### WHAT IS IMPORTANT KNOWLEDGE TO HAVE?

1. Specific information on:
  - past history (i.e. refugees)
  - family makeup/structure
  - child rearing practices/expectations/values
  - attitudes towards disability
  - role of education
  - socioeconomic background
  - language spoken, slang used
  - inherited customs
  - learning styles
  - ways of thinking
  - norms and beliefs (i.e. appropriate behavior).
2. Community support and other resources available to the cultural family (i.e. ICA, extended family, place of worship, school, traditional medicine).
3. Specific constraints on time, setting and resources for each family.
4. How your own culture (professional training and upbringing) relates to the family's culture (similarities and differences).
5. The type of professional expertise that is valued by the culture (i.e. academic, physical, medical).
6. Resources that are available to you as a professional (i.e. ICA, VIDEA, families).

### HOW DO YOU IMPROVE YOUR KNOWLEDGE BASE?

1. Workshops.
2. Connecting with your local cultural resource center or person (i.e. Inter-Cultural Association, ICA).
3. Accessing relevant literature (i.e. ICA, VIDEA, library, families).
4. Experience.

## Sample Workshop Handouts

### WHAT ARE IMPORTANT SKILLS TO HAVE?

1. 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.).
2. Reading verbal and non-verbal cues to ensure accurate assessment of needs.
3. Observing, understanding, and accurately reporting particular cultural behaviour.
4. Interacting and advising families on a course of action (i.e. treatment) that respects cultural expectations and practical limitations.
5. Using translators and cultural informants effectively.

### HOW DO YOU IMPROVE YOUR SKILLS?

1. Improve your knowledge and self awareness.
2. Take time to build relationships.
3. Always pay attention to non-verbal cues and subtle messages.
4. Ask families what they would like.
5. Specific training when available.

## Sample Workshop Handouts

### WHAT ARE IMPORTANT AREAS OF SELF AWARENESS?

1. Identifying biases in your own culture (attitudes and expectations from professional training and upbringing).
2. Being sensitive to stereotypes of different cultures (i.e. all are fatalistic, lazy, have a strong extended family, are hardworking).
3. Being aware of your own personal and professional boundaries and how these impact multi-cultural families (Have you done all that you can do?).
4. Being able to accurately judge different values and practices (i.e. some traditional medicine is respected while others may not be).
5. Realistically estimating your own limitations and degree of knowledge and seeking help or additional knowledge if needed.

### HOW DO YOU IMPROVE YOUR SELF AWARENESS?

1. Workshops.
2. Openness and willingness to work with families from different cultures.
3. A basic respect for people and differences.
4. A desire to do the best that you can for children and families.



## Sample Workshop Handouts

### BARRIERS TO HEALTH CARE

- DIFFERENT CULTURAL BELIEFS
- LANGUAGE
- TRANSLATION / INTERPRETATION
- TAKING TIME OFF WORK
- FINDING AND PAYING FOR CHILD CARE



## Workshop Planning Resource

### The Quick Instructional Planner by Peter Renner, Vancouver, BC Training Associates (1988)

Before you embark on designing a workshop for health service professionals (or any other audience), we highly recommend that you obtain a copy of this resource and use it to guide the workshop development process. Peter Renner, the author, describes *The Quick Instructional Planner* as:

*... a learn-as-you-go guide that takes you from rough idea to well-crafted course plan ... loaded with worksheets, planning charts, check lists, brain teasers, and helpful tips ... it systematically moves you through what appears to be a confusing maze of planning decisions:*

- Where do I start?
- What content should I include?
- What is important and what is 'nice to know'?
- How do I use content experts?
- How can I involve others in the planning?
- How do I sequence course components?
- Which training technique is most suitable?
- How do I create learner-centered training?
- How do I gauge the time needed for each part?
- When and how do I evaluate student learning?
- How do I keep track of the resources needed?

## Reference and Resource List

### Working with Families of Different Cultures

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# Step 7:

## Evaluate the community education programs and workshops



Step 7 is an  
evaluation  
step

An evaluation is carried out by the Project Coordinator to assess the effectiveness of the community and health care professional education programs and workshops. Persons involved in the education programs and workshops will be interviewed to:

- examine the effectiveness of the research process to involve the community, and to determine the barriers faced by families with a child with a disability and by health care professionals participating in the *Children Enabling Change* program; and
- investigate the strengths and weaknesses of the education program delivery.

Project Coordinator  
carries out an  
evaluation of the  
education programs  
and workshops

### Why Conduct an Evaluation?

Evaluation is an important step in the overall process of strengthening community development. It ensures that people keep focused and take a critical look at what is actually being done. Once a project is launched and time passes in the development stages, it is easy to lose sight of the original goals.

Evaluation will help  
ensure the education  
program goals were met

An evaluation also provides the opportunity to check that the results of the project in fact reflect the results of the research. Evaluating the workshop is important to ensure that the goals of the workshop were met, and that the people taking the workshop were satisfied with the information they received.



In the workshop planning resource, the *Quick Instructional Planner* (1988), author Peter Renner devotes an entire chapter to the evaluation process. He states:

“The evaluation concentrates on the core elements of the course process and content. By evaluating the process, you answer ‘How do the learners view the course? What feedback can they give the trainer (and the designer)?’ By evaluating the content, you find out ‘What has been learned and how far have the learners progressed toward mastery of the objectives?’

Before proceeding, decide what type of evaluation is needed. Some sort of process evaluation is a must for any course, especially a new one. You need to know how well your design worked under fire. The trainer and sponsors also have an interest in that information. Most of all, the learners are entitled to be heard from. Their feedback is valuable information.”

## How to Climb Step 7

These practical pointers, taken from successful *Children Enabling Change* programs, will assist you in planning for your own community program.

Examples of two evaluation forms are included at the end of this Step. The first is designed specifically for direct feedback by workshop participants, to be filled out on-site at the conclusion of the workshop. The second is designed as a general community evaluation tool. It can be used:

1. at a community “town hall” style meeting, where results of the research are shared and any educational materials resulting from the project are distributed, and
2. to collect feedback on an individual basis from families and other community members who have participated in various steps of the project.

The evaluation process will help you determine how successful you have been in using the community research findings to meet the identified needs of your community. You may want to have the community evaluation form translated into the appropriate community language.

Note that the return rate of questionnaires which participants are expected to return by mail is typically very low. You can increase the rate of return by:

- asking for completed evaluations to be handed in at the end of the workshop;
- conducting face-to-face interviews; or
- providing self-addressed, stamped envelopes.

## Comments from Actual Evaluations

We are indebted to the cross-cultural communication specialists of the Inter-Cultural Association of Greater Victoria (ICA), who took the lead role in both designing and delivering a most successful workshop for Queen Alexandra Centre for Children's Health (QACCH) health care professionals. The following workshop evaluation comments from health care professional in attendance speak for themselves:

“I suggest we work more closely in increasing our knowledge base and the resources available through ICA in Victoria and elsewhere. Working in support of the clients we serve in a culturally sensitive way means knowing what is available.”

“I would like more information on different cultures to help us health professionals to understand their perspectives and beliefs.”

“I would like to see this information offered at the University of Victoria for other nursing students.”

“I would like to visit other cultural communities (i.e. at the University of Victoria we were invited to places such as the Sikh temple to have discussions and to eat). This is a valuable project that must have taken great energy and creativity to pursue.”



"This workshop was an eye-opener to all that must be considered to effectively support those from other cultures. I will definitely use ICA as a resource in future dealings with other cultures."

"I will visit ICA. My husband and I have often talked about being volunteers in some way with this group. I would like to know more. This could easily be an all day workshop. Thank you for all your sharing and knowledge (and the food was fabulous!)."

### Comments from Actual Evaluations

The workshop was very helpful in providing information on the importance of cultural awareness in the workplace. The workshop was well organized and the information was presented in a clear and concise manner. The workshop was a great opportunity for me to learn more about the importance of cultural awareness in the workplace. The workshop was very helpful in providing information on the importance of cultural awareness in the workplace. The workshop was well organized and the information was presented in a clear and concise manner. The workshop was a great opportunity for me to learn more about the importance of cultural awareness in the workplace.

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## Sample Evaluation

### Evaluation

#### For Working with Families of Different Cultures Workshop

1. Did you find the workshop useful to you as a professional?
2. What part of the workshop was most useful to you?
3. What part of the workshop was the least useful? Do you have any suggestions for improvement?
4. Do you have any suggestions on how to strengthen the links between the various cultural communities in Victoria and your service group?
5. Any other comments?

## Sample Evaluation

### *Children Enabling Change* Community Evaluation

1. Do you think that the *Children Enabling Change* Project and resulting materials have helped you to better understand the needs of multi-cultural families with people with disabilities? Please explain.
2. In your opinion, could these materials lead to better community education and greater awareness of disability issues in multi-cultural communities? Please explain.
3. Will these materials increase the awareness of available services in multi-cultural families? Please explain.
4. Is the 3 Step brochure easily understood and accessible to multi-cultural families? Please explain.
5. Is the style (presentation and graphics) of the materials appropriate and user friendly for multi-cultural families? Please explain.
6. Does the Resource Guide enhance access to disability resource information for multi-cultural families? Please explain.
7. Do you think that the 3 Step brochure, Resource Guide, Overview and Action Plan Manual will help build stronger links between multi-cultural communities, the Intercultural Association of Greater Victoria (ICA), Queen Alexandra Centre for Children's Health (QACCH), Capital Region District Health (CRD), and community agencies? Please explain.
8. Do you have any further comments or suggestions on the materials, the project, and /or the continued partnership? Please explain.

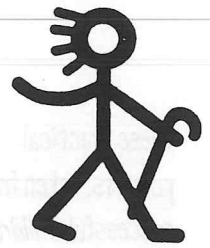
*Thank you for your participation in the project.  
It would not have been possible without you!*

# Step 8:

## Set up a disability information network linking the community to professional health care services

In Step 8, the project focus team meets with community members and health care professionals to devise culturally appropriate strategies for sustaining the program, with special attention directed to increasing involvement in these programs of persons with a disability. Examples of program-sustaining strategies might include:

- establishing a once-a-year workshop in the community and children's rehabilitation institution;
- developing new alternative research and education programs; and
- establishing a more permanent cross-cultural infrastructure between the community and professional health care services.



Step 8 is an action step

Devise culturally appropriate strategies for sustaining the program



# How to Climb Step 8

These practical pointers, taken from successful *Children Enabling Change* programs, will assist you in planning for your own community program.

Create and strengthen sustainable partnerships; build on existing programs

One of the keys to success in a community-based project like *Children Enabling Change* is to create and strengthen sustainable partnerships that fit into activities that are already established and functioning in the community. Building on existing programs promotes community development, and is an effective use of both time and resources. Working with established community resources will also help to avoid unintentional duplication of existing services.

It will be helpful for your Steering Committee team to liaise with key community resource agencies, to explore how together you might promote more effective linkages between agencies and your multi-cultural community, thus improving the flow of information and access to appropriate services.

For example, the *Children Enabling Change* project in Victoria engaged in discussions with the Resource Centre for Independent Living, an organization that publishes a general resource guide of services for persons with disabilities for the Victoria community. As a result of these discussions, the Resource Centre for Independent Living will take on the task of updating the *Children Enabling Change Getting Help: Victoria Resource Guide*, which was initially designed primarily to serve multi-cultural communities, as part of its mandate of service to the broader Victoria community.

In addition, the project is also liaised with The Queen Alexandra Centre for Children's Health (QACCH) and the Capital Health Board to amalgamate all resource guides using the same format, similar language style, and incorporating multi-cultural information. The resulting resource guide would serve a larger community and would be updated regularly by the Resource Centre for Independent Living.

Another example of successful information networking resulting from the *Children Enabling Change* program in Victoria are the strengthened linkages between the Inter-Cultural Association of Greater Victoria (ICA), QACCH, the School of Child and Youth Care (SCYC), University of Victoria, and the Capital Regional District (CRD). In addition to accessing increased knowledge from the research results, these institutions are now aware of

9 the wide range of resources and support that can be accessed through the ICA.

One of the strongest linkages in Victoria has resulted from the need identified through project research for qualified interpreters who have both an understanding of medical terminology and culturally-based health practices, and who are trusted by community members to maintain confidentiality. A need was identified both for training of interpreters in basic medical terminology and knowledge and confidentiality issues, and for training of health care professionals on how to use interpreters effectively. The opportunity for ICA to supply both cultural sensitivity training to health care professionals and specialized health care interpretation services for multi-cultural clients is being explored.

9 Further talks and information sharing with interested parties is resulting from distribution of information from the *Children Enabling Change* project. For example, a similar workshop for health care professionals is scheduled to take place at Sunnyhill and the BC Children's Hospital in Vancouver, and brochures following the format of the Victoria 3 Step brochure are to be developed for Vancouver and the Lower Mainland using information provided by Mosaic and the Immigrant Settlement Services (ISS) in their Red Book. Mosaic and ISS are two multi-cultural agencies in Vancouver. The Red Book is a comprehensive resource guide of service agencies in the Lower Mainland, including a section specific to disabilities.

For information on the Red book or to order a copy call:

Information Services Vancouver  
tel (604) 375-6331  
TTY (604) 375-0885  
Fax (604) 660-9415  
e-mail 73174.2234@compuserve.com

or contact:

MOSAIC  
1720 Grant Street, 2nd Floor  
Vancouver, BC V5L 2Y7  
Tel. (604) 254-9626  
Fax: (604) 254-3932

the Washington State Department of Health  
through the C.A.

One of the greatest obstacles to action has resulted from the  
lack of a coordinated effort. The various groups, working in  
isolation, have been unable to coordinate their efforts. The  
interdisciplinary approach, which has been the result of the  
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Further steps are necessary to bring about a more  
coordinated effort. The various groups, working in  
isolation, have been unable to coordinate their efforts. The  
interdisciplinary approach, which has been the result of the  
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has been the result of the collaboration of the various groups.

Information on the various groups is available on request.

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For more information, contact the Washington State Department of Health.  
Phone: (206) 462-1234  
Fax: (206) 462-1234  
E-mail: info@wsh.wa.gov

For more information, contact the Washington State Department of Health.  
Phone: (206) 462-1234  
Fax: (206) 462-1234  
E-mail: info@wsh.wa.gov



# Step 9:

## Evaluate Step 8, and reassess Steps 1 to 8



Step 9 is an  
evaluation  
step

In Step 9 a summative evaluation is carried out by the Project Coordinator. All persons involved in the program are interviewed to determine whether the project's objectives identified by the community have been met, and to examine any residual disability barriers affecting either families with children and other family members with disabilities, or professionals working in the community.

Project Coordinator  
carries out a  
summative evaluation

## How to Climb Step 9

The Project Coordinator completes this final step through a series of evaluation meetings and discussions, and then synthesizes the results into a final project report.

Feedback from the following sources should be considered:

- project Steering Committee
- research interviewers
- families interviewed
- other community members interviewed
- health care professionals interviewed
- evaluation of workshops
- evaluation of other educational strategies (publications, ads in community newspapers, outreach to service clubs etc.).

These practical  
pointers, taken from  
successful *Children  
Enabling Change*  
programs, will assist  
you in planning for your  
own community  
program.

## Project Coordinator's final report

The Project Coordinator's final report should address the following:

- A project overview
- A description of the project goals
- Were the goals met?
- Are the expressed needs of children with disabilities and their families being addressed by the project outcomes?
- Process: what worked? what didn't work?
- Lessons learned
- Were there any unexpected outcomes resulting from the project?
- What community linkages have been established, and how will they continue?

The report can then be shared at a "town hall" meeting, and used as a springboard for the community to explore its next development priority.

On the following pages are the "Lessons Learned" and "Summary Comments" sections from the final report of the initial Children Enabling Change project, to provide you with a sample of the report style and some valuable tips from the Project Coordinator to assist you with your own project.

## Excerpt from Children Enabling Change Final Report

### 6. Lessons Learned

Some of the lessons learned during the project are listed below.

#### How to Involve Families and the Community

- ensure that the interviewers are trusted and respected within the community and are personally committed to the project;
- contact participants personally and in writing and have the interviewers follow up with personal contact a few days before the scheduled meeting time;
- establish regular meeting times at the beginning of the project;
- provide child care, food, and transportation to and from meetings;
- keep meetings focused and meaningful;
- make meetings interactive by providing a comfortable environment, translation and culturally appropriate facilitating techniques;
- provide feedback to participants after the meeting in terms of a summary and action plan;
- take time to truly listen to their feedback and adapt your plan accordingly;
- ensure that the participants see the benefit of the research by providing them with tangible results.

#### Evaluation /Research Process

- spend time sensitizing all of the interviewers to their own issues associated with disability and discuss how these issues relate to their specific cultural group;
- provide practice sessions for the interviewers to ensure that they are comfortable asking the questions, to discover if the questions are appropriate, and to prepare them for potential responses, both positive and negative. These sessions will help prepare the interviewers for real life

situations and help them gain personal clarity and confidence;

- involve select families and community members in the refining of the questionnaire;
- ensure that the interviewers understand why the research is important, and explain why participants need to answer as many of the questions as possible (without biases);
- reinforce and support the need to establish culturally appropriate relationships and trust with the participants (For example, more than one visit, bringing a gift, helping out with tasks while doing the interview, reassuring confidentiality);
- when looking for participants for the research, personal referrals are most effective;
- keep the interview questionnaire short, about 30 minutes is sufficient;
- have a regular monthly progress meeting for the team members to provide support, keep people motivated, maintain clear communication and ensure that things are progressing as they should;
- involve the interviewers in the analysis of the data, determination of outcomes and dissemination back to the participants.

### Project Process

- ensure that goals, objectives, roles and responsibilities, and timelines are clear from the beginning and that newcomers are sufficiently briefed;
- ensure that all of the partners and team members are aware of the budget and how it is to be disseminated. Updates should be provided on a regular basis;
- have one central person coordinate training and communications. It is important that everyone feels that they can discuss their issues with this person and that this person is able to detect any discomfort or subtle hints of negativity or anxiety as it may not be deemed culturally appropriate for someone bring up certain issues;
- keep a written record of all meetings (their intent and outcome) and list who was present;

- provide for double the time if you wish to effectively involve several partners and/or families and communities;
- a focus on children is a good entry point as most cultural groups are invested in their children. Elders and/or seniors may also work as entry points;
- keep a separate record of all of the research participants addresses to ensure that confidentiality is not compromised while enabling information and outcomes to be sent back to all of the participants;
- facilitate ongoing promotion and partnership building to ensure long-term outcomes and sustainability.

## 7. Summary Comments

The Children Enabling Change project has successfully met its initial objectives of designing delivery and evaluating culturally grounded CBR education programs for community members and health care professionals.

While the community education process took a different form than initially conceived, this reflected the wishes of the communities, and resulted in a series of information materials that have been well received by both community members and service organizations. The two sets of information materials and one community process guide resulting from the research and evaluation have laid the foundation for a stronger network of partnerships between families, cultural agencies, health care organizations, and universities in Victoria and Vancouver. The duration of the project was extended from two years to three and a half years. While this created difficulties in extending the budget, it allowed for the project pace to be set by the families and community agencies. This was especially important because of the sensitive nature of the projects' focus on disability and the associated challenges of overcoming fear and suspicion in the communities.

Workshops will continue to be organized in Victoria, the resource guide has been taken over by RCIL and the QA Foundation, and dissemination funding has been secured to promote the project through partnerships with families and service organizations in Vancouver.



All of us involved in the initial *Children Enabling Change* project extend our best wishes to your community for a strong and beneficial outcome to your project.

We conclude with these inspiring words from the mother of a child with a disability from Victoria's Indo-Canada community, whose life, and that of her child, were changed forever by *Children Enabling Change*.

### HERMINDER'S STORY

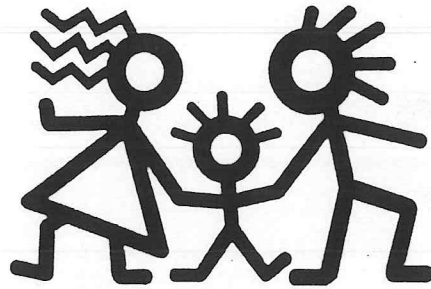
Herminder is a member of the Punjabi community of Victoria. She is the mother of three children and has been in Canada for many years now. Her oldest son Mainvir was born with a disability. He has what is called "Cerebral Palsy" and "Arthrogryphosis". Mainvir is in his teens now, but due to his disability he requires help with moving, dressing, eating, speaking and toileting.

"I want to thank the *Children Enabling Change* project. It has changed my life. At the beginning, when Michele first came to see if I wanted to be involved, I was scared. I always stayed at home with Mainvir. I didn't know what people would think, especially in my community. I didn't want to make it more difficult for my family. My English was also very poor and I felt very self-conscious. Life was very hard. I want to cry when I think about how hard it was. But now, because of the project, I know that I am not to blame and that you can still have a life even if you have a child with a disability, and that there is lots of help out there if you know how to get it.

Before, I didn't know that I could get someone to take Mainvir out and help take care of him. I also didn't know that he could use a special taxi or bus to go places or that many places have money that you can ask for when you need help paying for certain things. These are only some of the things that I found out from the Resource Guide that they gave me. It has helped make our life much easier. I have also been able to share this information with other moms who are having a hard time, though there are a few of them who still don't want to talk about it much. It takes time I think, but it is always useful to know what services are out there.

Because of the project, I also went to ICA to take English classes to make my English better, and now I have a job working at a place that helps adults with a disability live on their own. I've never could have done this before. It is a really good job. I am learning lots about helping Mainvir to be more independent.

Again, I want to thank Michele and Philip for everything. This project has really changed my life. Life is so much better now, not so hard."



“...a mentally or physically disabled child should enjoy a full and decent LIFE, in conditions which ensure DIGNITY, promote SELF-RELIANCE and facilitate the child's active PARTICIPATION in the COMMUNITY.”

UN Convention on the Rights of the Child  
Article 23.1



“If we could act in a spirit of solidarity recognising the principles of human equity, if we could bring services to all in need, if we could contribute to a better quality of life, reduce their dependency and transfer power to them, then we would restore to disabled people their right to a life with dignity.”

Einar Helander  
“PREJUDICE AND DIGNITY: An Introduction to Community-Based Rehabilitation”





It is necessary to recognize that the rights of the child are not only a right to life, but also a right to a life of dignity and respect. The rights of the child are not only a right to life, but also a right to a life of dignity and respect. The rights of the child are not only a right to life, but also a right to a life of dignity and respect.

UN Convention on the Rights of the Child  
Article 23.1



"We should not be afraid of disabilities. It is not the disability that makes a person different, but the way we react to it. We should not be afraid of disabilities. It is not the disability that makes a person different, but the way we react to it. We should not be afraid of disabilities. It is not the disability that makes a person different, but the way we react to it."

Elmar Helander  
"PREJUDICE AND DIGNITY: An Introduction to Community-Based Rehabilitation"

