

# OVERVIEW



# Children Enabling Change



EDUCATION, ADVOCACY, AND ACTION PLAN  
FOR CHILDREN WITH DISABILITIES  
AND THEIR FAMILIES  
IN MULTI-CULTURAL COMMUNITIES

# OVERVIEW



# Children Enabling Change

This booklet is intended to introduce you to the philosophy, goals, and structure of the Children Enabling Change program. The accompanying 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 Overview booklet, the Nine Step Action Plan Manual, the Victoria Resource Guide, and the 3 Step Brochure, which has been translated into Chinese, Vietnamese and Punjabi.

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# What is Children Enabling Change?



**Children Enabling Change** is a community-based disability education, advocacy, and action program for children from cultural minority groups, their families, and the health professionals who provide service to them.

Children Enabling Change incorporates principles of basic research, community development, and the United Nations Convention on the Rights of the Child, and thus can be used in a variety of community-based initiatives.

*"...a practical  
model of  
community  
partnership  
in action."*

Even after the Decade of Disabled Persons, integration still presents a great challenge for persons with impairments, and many barriers have yet to be overcome. **Children Enabling Change** provides a practical model of community partnership in action. It focuses on improving the quality of life for children with disabilities, their families, and other community members affected by disability. It encourages cultural minority communities and health care professionals to work together to access existing services and to strengthen effective communication and action.



**“CBR** *is a learning process,  
not a blueprint or a ready-made solution.  
It calls for flexibility,  
taking into consideration the social, cultural  
and economic situation,  
the circumstances of disabled people,  
the country's existing services and personnel  
and its phase of development,  
priorities and policies.”*

Einar Helander

“Prejudice and Dignity:

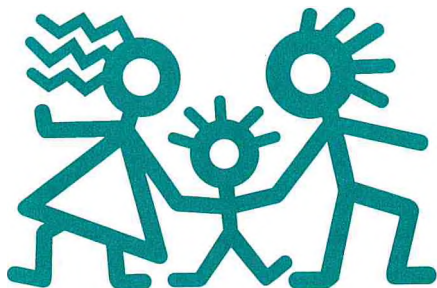
An Introduction to Community-based Rehabilitation”

**Children Enabling Change** is based on research facilitated by the **Inter-Cultural Association of Victoria (ICA)** in three BC communities: the Chinese and Indo-Canadian communities in Victoria, and the African community in Vancouver.

The program was developed in partnership with the **University of Victoria's School of Child and Youth Care (SCYC)**, and the **Queen Alexandra Centre for Children's Health (QACCH)**, Victoria's only children's rehabilitation institution. Development of this program was funded through the **British Columbia Health Research Foundation (BCHR)** as part of its ongoing commitment to multicultural health promotion initiatives.

**Children Enabling Change** is based on a community-based rehabilitation (CBR) model. CBR programs promoting education were initially developed by the **World Health Organization** (Helander, Mendis, & Nelson, 1979) as a way to share important information to meet the needs of children with disabilities and their families within a community context.

*Community-  
based  
Rehabilitation  
Model*



CBR is a system that promotes positive community change towards children, youth, and adults with disabilities, including:

- improving service delivery to reach all in need.
- providing more equal opportunities for people with disabilities.
- promoting and protecting the human rights of people with a disability.

For example, CBR promotes:

- the right of people with disabilities to enjoy health and well-being, and to develop the full extent of their physical and mental capacities.
- the right of people with disabilities to live within their communities and to fully participate in educational, social, cultural, religious, economic, and political activities.
- the integration of children in need of special support in ordinary schools.
- the provision of employment opportunities and fair wages for adults with disabilities.



# What does the term “Disability” include ?



In Canada, the term “disability” covers a wide variety of difficulties. Disability may mean something different than it did in your country of origin. In Canada, difficulties are classified as disabilities if the condition prevents the person from doing things that he or she would otherwise be able to do.

Some examples include:

- delayed or slow development (for example, not sitting alone by 9 months, not walking by age 2, or unable to read or talk until very late)
- difficulty with speaking or with understanding what others are saying
- clumsiness or uncoordinated movement (falling repeatedly)
- difficulties with drawing, cutting, writing, etc.
- hyperactivity (excessively active)
- difficulties with learning
- behaviour problems
- mental difficulties
- constant strange behaviour (screeching, flapping, etc. i.e. autism)
- eating difficulties (can't chew properly, chokes while swallowing)
- having difficulty getting around
- difficulties seeing or hearing.

“A disabled person is the one who in his or her society is regarded or officially recognized as such, because of a difference in appearance and/or behaviour, in combination with a functional limitation or an activity restriction.”

Einar Helander  
“Prejudice and Dignity:  
An Introduction to  
Community-based  
Rehabilitation”



Most disabilities are caused by a health condition, such as a disease or chronic illness, a trauma, a physical difficulty before or at birth, or by malnutrition. Environmental factors and social disadvantages such as poverty and restrictions of human rights often increase the extent of the disability .



*"Different cultures perceive disability in different ways."*

Different cultures perceive disability in different ways. For example, the culturally accepted practice of ritual scarification within African society may create a social disability for African-Canadians. Also, in some cultures certain disabling conditions may be so common as to seem unimportant. For example, severe breathing difficulties are very common in many countries and even though these disabilities can be treated in Canada, many persons from cultural minority communities do not see this as a disability and therefore do not seek treatment.

# Why was the Children Enabling Change program developed?

The Children Enabling Change program was developed to meet the need for improved cross-cultural health care as identified by both cultural minority families with a child in need of special support and by rehabilitation professionals working with these families. Health and social service workers are realizing the importance of becoming more aware of the particular needs of cultural minority groups. Also, in ratifying the United Nations Convention on the Rights of the Child, the federal and provincial governments of Canada have pledged themselves to supporting and protecting children with disabilities, particularly at the family, community, and cultural levels.

In order to work effectively with families and children from minority groups, health service professionals need the support of practical and effective training in cultural sensitivity. When ongoing opportunities to learn about and appreciate other cultures are not available to professionals, cross-cultural differences in

*"As Canada's multi-cultural population increases, so does the need to improve cross-cultural health care."*

*"Health service professionals need the support of practical and effective training in cultural sensitivity... to build effective cross-cultural relationships with children with disabilities and their families."*

attitudes and health practices often go unrecognized or are misunderstood. This in turn creates unintended barriers to effective interaction between health practitioners and their cultural minority clients - and when practitioners serve clients with a disability who belong to a cultural minority group, the obstacles may be even more pronounced when encountering culturally-based negative attitudes about disability.

Health professionals who are unaware of their own culturally-based attitudes and assumptions about health care and disability are apt to experience ongoing difficulties in their attempts to build effective cross-cultural relationships with children with disabilities and their families. Most of these difficulties stem from the lack of cultural understanding required to appreciate and negotiate cultural differences in language, beliefs, and patterns of interaction. Blocked by an inability to communicate effectively, practitioners may become frustrated when, for example, a cultural minority family fails to follow a prescribed course of treatment for their child with a disability, or does not return for follow-up consultations.

Cultural differences may also impede minority families caring for children with disabilities from making even initial contact with existing health services. For example, families who have relocated to Canada from another part of the

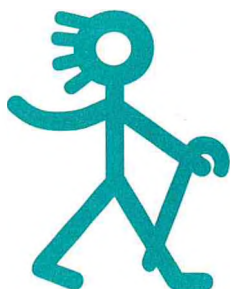
world may not be aware of public services available to children with disabilities here in Canada as these were not available in their home country.

In some minority cultures, there may also be negative attitudes toward persons with disabilities that reinforce family feelings of guilt, shame, and worthlessness. These families may feel too ashamed to allow their children with disabilities to take part in activities outside the home, or to seek support from health professionals for these children.

“ If we could all **ACT**  
in a spirit of **SOLIDARITY**,  
recognising the principles of human **EQUALITY**,  
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"



# What are the **goals** of the program?

The goals of **Children Enabling Change** are:

- to raise awareness and acceptance of disability in minority culture communities,
- to promote culturally appropriate access to and effective utilization of available services for children with disabilities and their families,
- to support advocacy for children and other persons with a disability in minority culture communities, and
- to improve the quality of cross-cultural interactions in health care for both clients and rehabilitation practitioners (ie. physiotherapists, occupational therapists, child and youth care workers, social workers, speech language pathologists, and infant development personnel).

*Awareness*

*Access*

*Services*

*Advocacy*

*Quality*

*Interaction*

The unique child-focused approach of **Children Enabling Change** builds on the strengths of minority culture communities to meet the needs of children with disabilities and their families in the following ways:

- by identifying and reducing existing barriers to satisfactory rehabilitation care for families with a child in need of special support;
- by raising the status and understanding of disability within the communities through improved community participation, both in programs for persons with a disability, and in ongoing community-based education regarding the causes, prevention, and treatment of disability;
- by developing a parallel program for rehabilitation professionals working with children and their families in minority culture communities, in order to increase the awareness and abilities of these professionals to meet the expressed needs of minority culture families.

Ultimately, the program seeks to build stronger, healthier communities through the positive example of children with disabilities enabling community change.

*Identify and reduce barriers to getting care*

*Raise community understanding, participation and education*

*Develop a program for rehabilitation professionals*



**“Rehabilitation** includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualization.



Rehabilitation includes not only the training of disabled people but also interventions in the general systems of society, adaptations of the environment and protection of human rights.



Protection of human rights is an obligation for the authorities of each country, for its communities and for every citizen.



Disabled people shall have the same rights to a life with dignity as others, and there must be no exceptions.



Special attention may be needed to ensure the following:

access to health and social services;  
to educational and work opportunities;  
to housing, transportation and to buildings;  
to information; to cultural and social life,  
including sports and recreational facilities;  
to representation and full political involvement  
in all matters of concern to them.”



Einar Helander  
“Prejudice and Dignity:  
An Introduction to Community-based Rehabilitation”



# Why does the program focus on children?



Experience has shown that, in many cultures, one of the most effective means of encouraging positive attitudes towards persons with physical and mental impairments is through community-based education and action programs focusing on children with disabilities. Children represent a culture's future, and rehabilitation care for children often produces the most immediate and noticeable effects. Thus, education and action programs emphasizing the benefits for these children are often a successful means of initiating community change and development.

For example, Vancouver's African community is made up primarily of newcomers to Canada from many different parts of Africa. Although there are a variety of needs and issues facing them, the community is still too young to have developed much internal structure. The **Children Enabling Change** program therefore served as a starting point for community development discussions. By meeting together to support the needs of children with disabilities, community members identified other common issues that could best be addressed through co-operative community action.

*"Education and action programs emphasizing the benefits for children are often a successful means of initiating community change and development."*



Children's disability education itself can therefore be used as an entry point for greater social change in the community. By observing children with a disability and their family helping themselves, community members learn how to make other positive changes within the community in support of persons with disabilities. Thus, children with disabilities become potential agents of community change and development for others with disabilities.

However, in cultural minority communities where attitudes are particularly biased against children with disabilities, the **Children Enabling Change** program may be adapted to reflect a more culturally acceptable entry point, such as placing the initial focus of rehabilitation care on elderly members of the community who have disabilities.

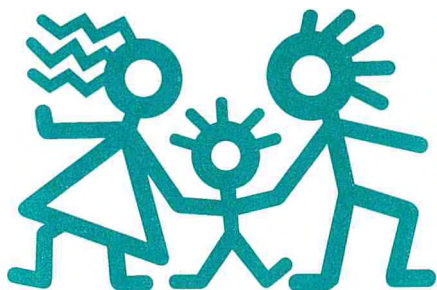
*"Children with  
disabilities  
become  
potential  
agents of  
community  
change ..."*

For example, in the Victoria **Children Enabling Change** project, the research data drawn from Victoria's Chinese-Canadian community indicated that these families faced considerable stigma associated with being a young person with a disability or having a child in need of special support. Children with mental difficulties were especially stigmatized, and many parents expressed feelings of shame, believing that their child's condition was caused by some previous personal wrong doing. One member of the research group noted that the Chinese character of disability, chan fei, translates as disabled (chan) and useless (fei). Consequently, many of the families in

these discussions felt considerably isolated from the rest of the Chinese community, and in many instances deliberately avoided taking their child in need of special support to public places, especially places where there would be many other Chinese people. Interestingly, participants in these discussions also disclosed that this stigma did not seem to generalize to older family members where disability was perceived as a natural part of aging.

Therefore, while activities focused on children with disabilities and their families are often the most effective entry point for community-based disability education programs, this may not be the most culturally appropriate approach for a specific cultural minority community. Each community will need to identify the most effective entry point upon which to build community awareness and acceptance of disability in support of these vulnerable children as well as other community members with disabilities.

*"Each community will need to identify the most effective entry point upon which to build community awareness."*



Shaping the  
program  
to fit your  
community

# Who is involved in **Children Enabling Change?**

## 1. Your Community

**Children Enabling Change** is, first and foremost, a program that belongs to you. Action should be based on decisions made by members of your community. Active participation in the program by community members who have disabilities and their families is vital. They should be involved in setting priorities, obtaining community commitment to address these priorities, and in the planning, monitoring, and evaluating of the **Children Enabling Change** program.

**Children Enabling Change** activities should respect and reflect your community's culture and social structures. They should be woven into the daily fabric of your community life.

**Children Enabling Change** encourages and supports your community, especially community members with disabilities and their families, to assume responsibility for:

- promoting and protecting the human rights of children and other community members who have a disability
- strengthening community rehabilitation referral services for health, education, and labour
- promoting, in culturally appropriate ways, accurate public information regarding prevention and rehabilitation of disabilities
- managing and evaluating your community's **Children Enabling Change** program.



*“ The teacher who has a blind child in the class;  
the primary health care worker who is expected  
to help a child with paralysed legs to walk;  
the mechanic who wonders whether the young man who  
cannot hear can be trained in mechanics;  
the traditional healer who cannot treat  
the strange behaviour of a child;  
the mayor who wants to plan an accessible community hall -  
all of these members of the community  
require knowledge about disabilities and  
guidance on how to assist disabled people.”*

UN 1994 Joint Position Paper  
“CBR: Community-Based Rehabilitation  
for and with People with Disabilities”

## 2. Professional Support Services

**Children Enabling Change** is based on the co-operative efforts of cultural minority children with disabilities, their families, and their communities, in partnership with appropriate health, education, vocation, and social services. Partnering with professional support services helps to strengthen the community resources you already have in place, and supports the transfer of knowledge and skills from external "experts" to the community. It will also assist those members of your community whose special needs require the skills of specialists outside the community, to benefit from the appropriate referral services.

*"Partnering  
with  
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community  
resources you  
already have  
in place."*

### Transfer of Knowledge and Skills

**Children Enabling Change** is built on the commitment of cultural minority communities to assist children with disabilities and their families. In order to meet this commitment, the transfer from professional support services of simple, practical, and comprehensive information is required. The knowledge and skills that are necessary to assist children with disabilities and to develop their practical functioning in daily life, include:

- facts about living with a disability, including child development, activities of daily living, schooling, vocational training, and employment issues

- facts about the causes and possible prevention of disabilities
- guidance on how to find and use resources within and outside the community.

This information must be accurate, understandable, and readily available. It must appeal to positive cultural and ethical values, and encourage positive reactions from community members.

## Referral Services

There will be situations where community members with disabilities will require skilled assessments, services, or facilities provided by specialists outside the community. **Children Enabling Change** promotes strong community linkages to referral services to ensure ongoing community access to required resources. **Children Enabling Change** also provides the opportunity to strengthen partnerships between referral services and to coordinate joint responses to community needs.

For example, the **Victoria Resource Guide for People with Permanent Difficulties or Disabilities** was created as a result of the **Children Enabling Change** programs of the Chinese and Indo-Canadian communities in Victoria.

*“Simple, practical, and comprehensive information is required.”*



*“ The referral services provided by the social, health, education and labour sectors should work in close collaboration to support the community and to make appropriate choices among the specialized services. ”*

UN 1994 Joint Position Paper  
“CBR: Community-Based Rehabilitation  
for and with People with Disabilities”

## Ensuring Community Ownership

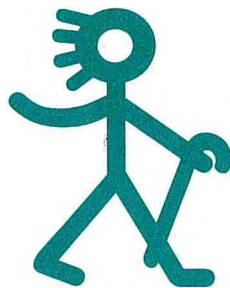
Information in itself is not enough. It must be communicated in ways that are appropriate for the culture of your community. You are the experts about your own community. For example, you have more knowledge and understanding than outside “experts” of how best to begin and sustain the process of changing any negative attitudes, habits or prejudices held by community members towards children and other persons with a disability.

Einar Helander, one of the global educators responsible for the development of the CBR model, has identified a number of key



strategies that promote community support for sustainable education and action programs:

- First, programs for children must fit into the specific cultural and social structure of the children's community.
- Second, education and action programs should be integrative and make use of existing services as the base for sharing information.
- Third, culturally sensitive programs should identify appropriate entry points for each specific cultural minority community in which action is taken.



*“ A CBR programme will be sustained when three factors come together: the articulation of a need, a response from within the community indicating readiness to meet this need, and the availability of support from outside the community. If one of these factors is missing, CBR will fail. One cannot expect community involvement without a perceived need, and there should be no support to the community unless it is willing to meet that need. ”*

UN 1994 Joint Position Paper  
“CBR: Community-Based Rehabilitation  
for and with People with Disabilities”





# The Nine Step Action Plan

Community  
Needs

Entry Points

Consolidate  
Team

Interviews

Community  
Consultation

Education  
Program

Program  
Evaluation

Information  
Network

Reassessment

You will find practical examples of each of Helander's key points in the Manual for **Children Enabling Change: Education, Advocacy, and Action Plan**, which this Overview booklet is designed to accompany. The Manual outlines a detailed plan for setting up and operating a **Children Enabling Change** program in your community, with practical examples and advice from the community members who organized B.C.'s first project. The Action Plan connects families who have children with disabilities, community support agencies, and health service professionals. Following the plan will strengthen your community's capacity to meet the needs of children with disabilities in practical and culturally effective ways. **Children Enabling Change** may also be useful as a blueprint for community action and partnership for other areas of expressed need.

If you would like additional copies of the Overview, Manual or other support materials such as the Victoria Resource Guide or the 3 Step brochures, please contact:

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“...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

