



Independent Living Promotion Kit

Independent Living Canada

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Introduction

The growth of the consumer movement in Canada in the 1970s is quite unique and interesting. Out of it developed a new appreciation of people with disabilities as important citizens with abilities and a new philosophy of the role of service providers and themselves as empowered consumers. The new philosophy was called Independent Living (IL). This document is an introduction to IL. It is designed to explain the basic IL movement. This philosophy is motivating for people with disabilities, their families and friends. For more detailed information, please visit IL Canada website at www.ilcanada.ca.

Since its inception in Canada, the IL movement has accomplished a great deal; but there is still more to do, and many more to involve. Hopefully, this kit will encourage you, and especially people with all kinds of disabilities to join the evolving IL Movement in their respective communities. The movement is growing worldwide, and IL Canada has member Centres in 27 communities in Canada.

This promotion kit is divided into four sections. The first one explains the IL approach and presents the history of the growth and development of the IL movement, both in the United States (US) and Canada. The second part reviews the IL Core Theme Areas: Information and Networking¹, Peer Support, IL Skills Development², and Research and Community Development³. Each IL Centre, also called an Independent Living Resource Centre, maintains its four core theme areas to respond to unique community identified needs. The third part provides a brief snapshot of the history of the development of several IL Centres in Canada and finally the fourth section talks about IL Canada.

Since its establishment in 1986, IL Canada has acted at the federal level as a national bilingual umbrella organization. We also work as catalysts for improvements and the removal of barriers to full participation for people with disabilities. We work with government on behalf of IL Centres and with people with disabilities in general.

¹ Formerly Information and Referral

² Also known as Individual Advocacy

³ Formerly Research and Development

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Part I

What is Independent Living (IL)?

IL Philosophy is an alternative approach to the traditional medical rehabilitation service delivery model. The IL Philosophy promotes and encourages an attitude of self-direction in consumers, so that they may be able to negotiate and access the community services and resources they require in order to participate as equal citizens in their community.

The IL Philosophy recognizes the rights of individuals with disabilities to assume risks and to make choices. It puts all decision-making right into their hands. Consumers are encouraged to identify and to achieve their own independent living life goals.

1. The Goal of IL

In 1985, at the first National meeting of Independent Living Centres, held in Ottawa Ontario, it was stated that the goal of the Independent Living Philosophy, known as IL was *“to promote and enable the progressive process of citizens with disabilities to take responsibility for the development and management of personal and community resources”*. The IL Movement aims to establish the means by which people with disabilities take control of their lives.

The fundamental goal of the IL Movement is to eliminate **social and environmental barriers**, which prevent people with disabilities from controlling their own lives. It is essential to destroy those barriers because it is the barriers and not the disabilities, which prevent people from living independently. The goal of IL is to shift attention from their disabilities, to the people and on what they can do for themselves and for others.

2. What Independent Living (IL) Means

a) For People with Disabilities

Stated simply: People with disabilities know what is best for themselves: Unlike traditional rehabilitation models, the IL model encourages people with disabilities to take control over their own lives. People with disabilities have the right to examine options, make choices, take risks, and even to make mistakes in the learning process. Through these rights and responsibilities, each person maintains his/her self-respect. The IL philosophy recognizes the reality that people with

disabilities have the same rights as anyone else and it allows people with disabilities the dignity of risk.

The IL Movement has developed its own unique identity in response to the traditional rehabilitation services model. According to the IL Paradigm, the problem does not reside in the individual, but often in the solution offered by the professional. In his 1979 research Gerben De Jong produced, Independent Living: From Social Movement to Analytical Paradigm which brought these concepts to the academic community.

According to the traditional medical model, physicians and other professionals are the experts one must obey. These experts take charge; they see people with disabilities as child-like, as weak and uninformed, people who are unable to run their own lives. In dramatic contrast, IL philosophy recognizes that people with disabilities can and does take actions in their own lives. IL has a self-empowerment, self-help method that leads to a new kind of social and political power.

b) For the Community at Large

Since the early 1980s, the IL Movement has prospered in Canada because it encourages and enables people with disabilities to participate fully in their community. IL philosophy fits in well with Canadian social and political beliefs of inclusion and equal human rights.

The IL Movement seeks to raise community consciousness. It helps remove social and environmental obstacles, such as the barriers around the stigma surrounding disability, the lack of access to proper education, chronic poverty and unemployment or under-employment, for people with all kinds of disabilities.

Economically, the IL model provides opportunities that enable consumers to have choices to leave institutions, develop self-management skills and reduced dependency on the public purse. Further, people can become contributors economically, socially, politically, spiritually and culturally to our social democracy.

3. What is the history of the Independent Living Movement?

IL Centres in the North American context originated in the university campuses of Berkeley California. Some students with disabilities realized that after graduating, they would no longer have access to the needed

services that they depended upon, in order to live in the community. Such services included among others, attendant care and accessible transportation. In 1972 to solve this practical problem, they organized themselves co-operatively in groups to support one another to guarantee the provision of these services. The provisions at the grassroots lead to over 200 IL Centres being established in the US

- The Canadian Evolution

Learning from the example set by people with disabilities, in the US, Canadians started to organize and lobby for full participation and true equality within Canadian society. These principles became central to the new movement which began in Western Canada with grassroots organizations that formed in Saskatchewan and Alberta in the early 1970s. In 1976, a national organization was formed called the Coalition of Provincial Organizations of the Handicapped, known as COPOH. It was later in 1980, at the COPOH National Conference, entitled “Parameters of Rehabilitation” that Canadians learned extensively about the IL paradigm from the theorist Gerben De Jong.

By 1982, the first IL Centre in Canada was established in Kitchener Ontario, sponsored by the Mennonite Central Committee-Ontario Branch (MCC). The MCC, with its concern for social justice issues, was very active within the IL Movement, particularly in Manitoba in the early days. Later in 1983/84, Centres were developed locally in different provinces. Centres were established, in 1984 in Winnipeg and Calgary, and plans also got underway for a Centre in Thunder Bay. By 1986, the Canadian definition of an IL Centre was strong and entrenched, with IL Canada (formerly the Canadian Association of Independent Living Centres) being formed in that year to serve as the umbrella organization for Centres. Since then, annual meetings and national conferences continue to be held to provide opportunities for learning and growth.

Over the next few years other member Centres from Toronto, Trois-Pistoles, Ottawa, Niagara and Kingston joined CAILC. In 1988, the Honourable David Crombie, the Secretary of State officially recognized the IL Movement in Canada.

What is unique in Canada, with respect to our citizens with disabilities, is our role in the process of social and policy changes. The focus on Individual Advocacy enables an IL Centre to play an important part in the

personal empowerment process of thousand of Canadians with disabilities. This enables consumers to have a stronger voice in articulating their needs and to play an active role in monitoring service delivery practices.

4. The Five Guiding Principles of IL Centres in Canada

IL is premised on the philosophy that all people with disabilities have skills, determination, creativity and a passion for life, yet many are unable to fully participate in economic, political and cultural life because barriers to full citizenship persist in Canadian society. These include outdated attitudes, inflexible laws and regulations, and a fragmented and uncoordinated approach to everything from hiring, to housing, to public transportation.

The Canadian IL Movement and IL Centres were founded on five principles. These five principles are: consumer control; cross disability; full participation and integration of all people with disabilities; community based; and not-for-profit.

a) Consumer Control

Those who believe in the IL philosophy insist on the right of people with disabilities to examine possible choices, make decisions, take risks, make mistakes and generally take responsibility of their own lives. IL Centres reflect this attitude in the principle of consumer control, which states that all centers and programs, as well as resources they provide are governed and controlled by people with disabilities. The majority of IL Centre Board members are people with disabilities, and the by-laws reflect this reality.

b) Cross disability

The IL Movement recognizes the fact that people with various disabilities have unique needs and face unique barriers. It also acknowledges that all people with disabilities have the same rights. Accordingly, IL Centres reflect this reality embraced in the principle of cross disability. IL Centres also strive to ensure programs, supports and accommodations respond to the needs of everyone, regardless of their disability or combinations of disability.

c) Community based

The IL Movement is a grassroots movement. The people who use the Centres in each local community are the ones who decide what needs have to be addressed and the best approaches to deal with barriers. This

community development approach applies to service development, evaluation, and promotion. Programs and services are designed to compliment existing community resources and services.

d) Promotion of Participation and Integration

Inherent in the philosophy of IL, is a human right to be included, which is the right of citizens to participate in the social, political, economic, academic, and cultural life of their community. Centres provide consumers with tools, support, resources, self-confidence, and self-management skills to enable the achievement of personal goals.

e) Not-for-Profit

Centres are non-profit organizations, with a volunteer Board of Directors and members who are committed to alternatives to existing service provision. IL Centres form partnerships with community groups.

These principles are the basis of the core theme areas outlined in the next section.

The IL movement and the philosophy on which it is based are not abstract concepts. Instead, IL is about a “way of living” for persons with disabilities who live in a society where many barriers remain. This approach is referred to as the “IL lens”, an approach that is applicable to all supports and services that IL Centres provide. The broadness of the core theme areas recognizes that services and programs and methods of delivery are unique and responsive to the needs of local communities across Canada.

Part II

What are the Core Theme Areas?

Each Independent Living Centre (IL Centre) offers programs and supports/services in four core theme areas, as outlined below.

CORE THEME: INFORMATION & NETWORKING

DEFINITION:

Information is the key to having choices, making decisions, and learning to take risks. The Information and Networking core theme promotes the Independent Living (IL) philosophy to consumers, their families, friends and support networks, community and governments by providing clear, accurate and up to date information that meets individual needs. This process is interactive; a “two-way street” that creates positive impacts for consumers and builds ongoing relationships between IL Centres and organizations in the community through the provision of current information on cross-disability issues.

The experiences of people with disabilities validate the information that is out there to further understanding.

PRINCIPLES FOR INFORMATION & NETWORKING:

- A response-orientated approach is required to answer community needs.
- To empower the individual with information in order to make informed choices.
- To work with an individual to reduce their isolation from the community, we can refer them to the appropriate resource to broaden their opportunities and horizons in the areas that **they** may choose.

Note: Information & Networking is often the first introduction an individual has to the centre and is frequently the gateway to other programs and services.

STANDARDS FOR INFORMATION & NETWORKING:

- Maintain and update information to provide current and precise information on a diverse number of programs and services issues (i.e. employment, housing, disability supports, etc.)

- Information to be provided in a variety of ways (i.e. brochure racks, community bulletins, website links, etc.)
- This collection of information to be promoted and open to the public
- Centre staff support to be available to respond to general inquiries and requests from consumers
- Provide information in alternate formats and plain language upon request to enable consumers to access information in a variety of formats (i.e. hard copies, information exchange through meetings or by phone, etc.) Responses are to be completed in a reasonable time frame.
- Provide open access to at least one computer connected to the internet. Trained staff/volunteers must be available to support the consumer if assistance is required.
- Create and distribute a newsletter to the membership and larger community, as deemed appropriate by the Centre, to be available in hard copy and electronic formats. Newsletter to be distributed at a minimum of twice per year.
- Demonstrated commitment to creating partnerships and networking in the community by:
 - Staff/volunteer involvement in appropriate community based activities (i.e. committees, boards etc)
 - Information forms as a means of updating consumers on a variety of topics;
 - Booth displays;
- IL Centres ensure full accessibility through using alternate formats, plain language, discussion, peer exchange and by sharing knowledge and experience. Supports and services could include, but are not limited to, the following: IL resources; disability related services; technical aids information; community & social service resources; information on government programs; computer & literacy training options; sports and recreation programs; referral services; and resources as requested by consumers and to be responsive to local needs.

CORE THEME: PEER SUPPORT

DEFINITION:

The Peer Support core theme is designed to provide opportunities for people with disabilities to share their knowledge and lived experiences. We recognize a peer as an individual who has had a similar or common experience and is willing to share the lessons learned” Peer Support also affords individuals the opportunity to reduce isolation, to develop leadership skills, and gives assistance to individuals in exercising their rights and responsibilities. Peer support can be offered individually or in a group, and can be provided on an ongoing and/or in a crisis-situation in an environment of mutual respect and trust.

Examples of peer support can include, but are not limited to, the following: self-help; problem solving; stress management; opportunities to join social activities (diners’ clubs, recreational groups); and as identified by consumers in local communities.

PRINCIPLES FOR PEER SUPPORT:

- Peer support is integral to the IL philosophy and is a methodology that is demonstrated throughout all centre programs and services.
- Within a supportive peer environment an individual can gain skills and self-confidence needed to overcome barriers.
- To encourage people with disabilities to speak with others and share their thoughts, concerns and hopes with each other, promoting exchanges and discussion between individuals who have lived the experience.
- Centres are to provide support that promotes integration and participation in the larger community.
- To encourage people to face new and possibly challenging situations

Note: It is recognized that each centre will be different in the degree of implementation as resources and the needs of the community are unique.

STANDARDS FOR PEER SUPPORT:

- Activities to be offered in a variety of forms (i.e. in person group, one-on-one, telephone network, on line message boards, etc.) depending on consumer preference.
- Offer personal growth workshops (i.e. communication skills, self-advocacy, etc.)

- Actively engage peers in planning, delivery, and evaluation of activities. (i.e. monthly group meetings, advisory committees, evaluations etc.)
- Develop groups of special interest to consumers based on the needs identified (i.e. parenting, women's groups etc.)
- It is strongly advised that an individual with a disability be in the position of coordinating peer support activities.
- Volunteers who are in mentoring relationships (i.e. one on one, board development, etc.) are trained to develop and demonstrate appropriate listening and sharing skills.

CORE THEME: IL SKILLS DEVELOPMENT

DEFINITION:

Communicating, negotiating, problem solving and personal management are all important aspects of daily life. The IL Skills Development as a core theme assists individuals to advocate on their own behalf, supports their choices, respects their decisions, and affords individuals opportunities to take risks.

The program also provides learning opportunities for dealing with barriers and discrimination so that persons with disabilities can know their rights and responsibilities, and can access services and training opportunities to live and participate in society.

PRINCIPLES FOR IL SKILLS DEVELOPMENT:

- To support individuals in learning to manage, coordinate and negotiate a wide range of community resources.
- To assist consumers to exercise their rights and to provide support to people in pursuit of their individual advocacy goals.
- To work with consumers to enhance their problem solving skills.
- To assist individuals in reaching their Independent Living goals by taking a pro-active, solutions based approach to conflict and problem solving.
- To provide tools, support and resources to create lasting positive change

STANDARDS FOR IL SKILLS DEVELOPMENT:

- Staff time dedicated to facilitating with individuals to advocate on their own behalf.
- Demonstrated commitment to provide opportunities for consumers to increase skills and/or self-advocacy opportunities as identified above. This can be accomplished by:
 - Skills building by one-on-one support or holding workshops for consumers on rights and self-advocacy (i.e. housing, social assistance, human rights, etc.);
 - Creating opportunities for the development of tangible skills (i.e. computer training, pre-employment skills, etc.) by accessing local experts and/or persons with disabilities – or providing in-house; and
 - Creating partnership in the community to refer consumers for training.
- Let the individual lead the process and decide the level of support. When appropriate staff or Volunteer to accompany individuals to initial meetings with organizations and service providers as a means of support in expanding their network and developing skills without creating dependence.
- Consumers may also find support in a number of areas: literacy; technology; crisis intervention; peer leadership; and other issues that are identified locally.
- Strive to work with diverse groups of people with disabilities, from various backgrounds etc.

Note: In some Centres, employment and volunteer recruitment opportunities are offered by a dedicated staff person or by other staff, while in others the IL Skills Development program takes on providing these supports.

CORE THEME: RESEARCH & COMMUNITY DEVELOPMENT

DEFINITION:

This area focuses on demonstrating IL models of services and delivery. The Participatory Action Research model most used in IL recognizes that persons with disabilities have expertise in determining what works and what does not. Consumer tested and validated information is the key to developing programs and services that benefit the whole community. Partnerships formed with individuals, community organizations,

governments, schools, universities and businesses support the realization of these goals. By working together, gaps in service can be determined and new options and solutions can be created.

Research and Community Development activities can include, but are not limited to: conducting research and demonstration projects; disability awareness training and facility/web accessibility audits; and crime prevention and abuse initiatives. It can also encompass developing new models of IL for various populations and environments in order to test new solutions and to provide unique and responsive methods of support at the local, regional and national level.

PRINCIPLES FOR RESEARCH & COMMUNITY DEVELOPMENT:

- To respond rapidly and effectively to the unmet needs of the community.
- Research will be conducted and/or participated in regarding a variety of issues that adhere to the IL philosophy and promote inclusion.
- Pilot projects must be done to identify unmet needs; Centres can then propose alternative service models.
- Research ethics must adhere to IL.

STANDARDS FOR RESEARCH & COMMUNITY DEVELOPMENT:

- Centres to develop and participate in community partnerships with other organizations/researchers, ensuring participatory action research.
- Commitment to research and community development demonstrated by:
 - communications with other groups and agencies in the community;
 - media releases and public speaking opportunities;
 - drafting of funding proposals to conduct demonstration projects;
- Demonstration projects/ initiatives must be developed responding to community needs and with an IL lens.
- Centres to offer disability awareness training sessions to the community.
- Centre staff/board/consumers to participate in public speaking events.
- Centre staff to facilitate media opportunities (print, radio, TV) to increase awareness of IL in larger community.

- Centres to organize forums for individuals to identify unmet needs as they see them.

Part III

How do you start a Centre?

The development process of each Centre is unique. There are steps to follow based on the guiding principles of IL. Here are some of the keys to the success of forming an effective Centre:

- 1) Gain the support of community and or/ church organizations by sharing information about IL
- 2) Gain the support of like minded groups and especially the support of people with disabilities.
- 3) Verify gaps in service provision through accessing collaborative community consultation processes
- 4) Remain flexible to best assess the needs of the various groups of people with disabilities.
- 5) Build a community based consumer controlled Steering Committee which can eventually evolve into an elected consumer controlled Board of Directors.
- 6) Set out a plan which doesn't duplicate services, but instead endeavors to address community gaps and needs as identified by people with disabilities in innovative, collaborative, and strategic ways.

As communities begin planning for an IL Centre and reach the stage where a steering committee is formed, IL Canada facilitates the exchange of support and information. The existing network of Centres plays an important role in this regard. In addition, IL Canada helps groups to find opportunities to develop skills and knowledge of the local consumers in the community.

1. The evolution of Centres

The *Centre de Vie Autonome de la Région Du Bas-St-Laurent* is in Trois Pistoles Québec, a town situated on the south shore of the St. Lawrence River, east of Quebec City. Through its involvement with what was then COPOH, a national organization of provincial organizations of people with disabilities interested consumers became aware of the IL philosophy. Members of the initial organizing committee sent delegates to the CAILC conference in 1987, in order to learn more about the IL Movement and to begin the development process. From humble beginnings, this vibrant Centre began. In 1988, over 150 interviews with consumers were carried out and the results clearly supported the establishment of an IL CENTRE in the area.

In addition to a well-established Centre in Val d'Or, Quebec, there are also newer Centres in Shippagan, New Brunswick, in St-Jean-sur-Richelieu, Quebec, and in Alfred, Ontario. These Centres give both regional and rural perspectives to the IL movement working with predominantly francophone populations.

2. Success stories

Thunder Bay was one of the founding members of CAILC in 1986. To complement the four Core Theme Areas they provide other supports to citizens with disabilities including self-managed attendant services for direct funding, employment and self-employment supports, and a Universal Design program.

The Independent Living Centre in St. John's is a very good example of the strength and wonderful community roots that nurture environments of growth and development. Their logo has three Black Spruce trees, one of Newfoundland's strongest trees, growing even when the odds are against it, because it is resilient, resourceful and adaptable it represents the spirit of a thriving community.

As in each IL Centre, their resources are also available to family members, care providers, professionals, students, community organizations, government departments and anyone else interested in disability issues.

One of IL Canada's newer Centres on the west coast is the Richmond Centre for Disability. Their Disability Links offer website information that is clear and concise, relating to organizations, resources, government, education, health questions and more. Further, there are links to websites related to municipal services, sports organizations, and international disability organizations.

Information sharing, and community consultation is central to the IL mandate. IL Centre supports people to make their own informed decisions. Each centre also researches new ways of designing services and supports.

Accordingly, some Centres have already celebrated their 20th anniversaries, while others are in the beginning stages of their development process.

PART IV

IL Canada and its mandate

Since 1986, IL Canada has helped coordinate the activities of the IL Centres in Canada. Governed by a Board of provincial representatives and members at large the IL Canada Board provides national leadership to ensure that the IL Movement thrives and grows to meet the growing needs of Canadians with disabilities. IL Canada supports the IL Movement by assisting and supporting staff and volunteers, developing training and resources for all IL Centres to share, linking Canada's IL Centres into a powerful network, and promoting the IL philosophy.

IL is about having choices, making informed decisions, growing and finding solutions that work for you, choosing where and how you want to live, taking risks, and responsibilities, and managing your resources.

We have a compelling vision of a Canada that is able to tap into the incredible resources of people with disabilities. We are working to empower citizens, and to remove barriers so that responsible, self-reliant people with disabilities can assume risks, make choices and contribute as they wish.