Impact:

Changing the Way We View Disability

The History, Perspective, and Vision of the Independent Living Movement in Canada

John Lord

Impact:

Changing the Way We View Disability

The History, Perspective, and Vision of the
Independent Living Movement in Canada

John Lord

Published by Creative Bound International Inc.
on behalf of
Independent Living Canada
1104–170 Laurier Ave. W., Ottawa, ON K1P 5V5
Tel: 613-563-2581 Fax: 613-563-3861 TTY: 613-563-4215
www.ilcanada.ca

ISBN 978-1-894439-45-9
Printed and bound in Canada

Impact: Changing the Way We View Disability was developed by a team from Independent Living Canada:

Traci Walters, National Director	Daniel Bilodeau, Interviewer
Christine Malone, Project Manager	Jihan Abbas, Researcher
Anna Quon, Writer of Consumer Stories	John Lord, Principal Writer

Pre-press and production services by Creative Bound International Inc.
Cover image © istock

This project is funded by the Government of Canada's Social Development Partnerships Program. The opinions and interpretations in this publication are those of the author and do not necessarily reflect those of the Government of Canada.

This book is also available in alternate formats. To inquire, phone 613-563-2581 or fax 613-563-3861 or email ilimpact@ilc-vac.ca

Library and Archives of Canada Cataloguing in Publication Data

Lord, John, 1943-
Impact : changing the way we view disability : the history, perspective and vision of the Independent Living Movement in Canada / John Lord.

Issued also in French under the same title.
Includes bibliographical references and index.
ISBN 978-1-894439-45-9

1. People with disabilities--Canada. 2. Canadian Association of Independent Living Centres--History. 3. Independent Living Canada--History. I. Title.

HV1559.C3L673 2008   362.40971   C2008-907429-7

Contents

Appendices

Preface

It is with great honour and privilege that I am writing the preface to this book. After working in the Independent Living Network, both locally and nationally, over the past 20 years, I believe this book has captured the evolution and essence of the Canadian Independent Living Movement while revealing its impacts on individuals and the community at large. As the slogan of Independent Living Canada—"Promoting a new perspective on disability"—suggests, we are continuing to create change. The Independent Living philosophy, which embodies consumer control, self-help, peer support, and barrier removal, turned the notion of pity and charity on its head. One community at a time, the development of local centres played a pivotal role in changing the way a community viewed its citizens with disabilities—and how citizens with disabilities viewed themselves. In the Independent Living model, the disability is not the problem but rather the disabling conditions in society. When barriers are removed, individuals with disabilities have greater choice and control over their lives. It is simply a matter of perception!

When I became the first executive director of an IL centre in Niagara in 1988, service providers/social agencies were actually opposed to the idea of an organization developing that was going to be run by, and for, persons with disabilities. In fact, many of these agencies firmly believed that persons with disabilities were not capable of such responsibility, keeping in mind that those very agencies provided services for decades, instilling that very attitude in the "clients" that they served.

Although there was real opposition from numerous agencies at that time, local service providers began to realize that many of their own consumers could benefit from the supports offered by the IL centre. Within a few short months, we could barely handle all the referrals from the once-opposed providers.

This was not unique to the Niagara community; it is a common story threaded throughout the histories of Independent Living centres. At each centre, consumers sent a message to the community that individuals with disabilities wanted more control in their services. Rightfully, they began running their own organizations. It has been proven over and over again, when individuals have more control over their services and supports, the greater are their chances of success—and naturally, skills continue to develop in the process. Independent Living is as much a process as it is a goal. That process in itself enabled thousands of Canadians with disabilities to feel a sense of pride (yes, disability pride) in the knowledge that they can contribute to the community and are valuable members of society.

Over the years, the IL movement has made an incredible impact on many individuals and their communities across the country. It only makes sense that when building the capacity of citizens within a community, the community naturally becomes richer, socially, economically, culturally, and politically. Individuals with disabilities, who once believed that their lives were rendered to the fringes of society and that they should be grateful for some food or basic shelter, transformed into confident, hopeful, and active residents, participating in their own communities and/or reinvesting their skills as leaders within the local IL centres that provided the original supports.

This "new perspective on disability" transformed individuals and communities. More and more, society is transforming and Canadians are on the cusp of recognizing that persons with disabilities want to contribute to all aspects of society and that society is better off for it. To that end, disability is simply a normal human condition, and all people, disabled or non-disabled, want a society with opportunities to live life to its fullest.

It was only natural that the initial focus of this book was based on the impact of Independent Living on individuals with disabilities, on communities, and on society in general. The book's author, John Lord, the project manager, Christine Malone, and IL Canada's research and policy consultant, Jihan Abbas, began this endeavour with the aim of uncovering the impact of IL on individuals and communities and documenting the story of the growth of IL Canada. IL centres sent in names of consumers, board members, volunteers, and staff members who were interested in telling their stories. As more and more interviews took place, new themes began to emerge. Each interview revealed a broader understanding and application of Independent Living, which in turn broadened the focus of the book. It began to take on a life of its own, and the stories shaped the collective consciousness of the Canadian IL experience.

The IL book itself has been transformed throughout the writing process, looking at not only the past and the impact the movement has had, but also on how the movement itself has been shaped by individuals, groups, and evolving social systems in a uniquely Canadian context. In the development of this piece, we learned that the growth of a movement, and the chronicling of it, is not a linear process, but rather a multi-faceted, ever dynamic experience to be explored and valued. As a result of this examination, we are building on the lessons learned and moving into the future to meet the challenges and seek new opportunities together.

I would like to thank John Lord, Jihan Abbas, and all those who contributed their insight and stories. I need to give a special note of thanks to Christine Malone, the Independent Living Impact project manager, who persevered in overseeing the successful completion of this project and the publishing/translation of this book. John Lord also spent many hours volunteering beyond the original timeframe to ensure the accuracy and completion of this book and for that we are grateful.

Independent Living Canada would also like to thank Human Resources and Social Development Canada's Social Development Partnership Program for providing funding for this initiative.

This book is dedicated to all those who played a role in the development of Independent Living Canada and its network of member IL centres, and to the potential that lives in all of us.

Traci Walters,
National Director, Independent Living Canada
(formerly the Canadian Association of Indpendent Living Centres)

Introduction

During the last three decades, the Independent Living movement has played a significant role in enhancing the lives of Canadians with disabilities. This book chronicles this movement since its inception in the late 1970s. It also highlights how the Independent Living idea of citizenship rights and full participation has had an enormous impact on Canadian communities.

In framing this book around Independent Living as a social movement, we show how Independent Living Centres across Canada ground the movement's vision in the everyday lives of people and communities. This is a story of resilience and possibilities, as people with disabilities take charge of their own lives and work with others to create positive change in their communities.

We used three main approaches in researching and writing this book. First, we reviewed all the relevant documents related to Independent Living in Canada. Second, we conducted numerous interviews with leaders in the movement, and spent time in conversation with people at selected Independent Living Centres. Finally, we invited members and consumers to share their stories with us. Some people sent us their written stories, while others were interviewed by our storywriter.

Once we had gathered all the resources and stories, we identified common themes across various sources of information. We reviewed these initial themes and eventually formulated 13 chapters. In Part I, we review the history and context of the Independent Living movement in Canada. In Part II, we explore the numerous ways that Independent Living has had an influence and impact across Canada. In

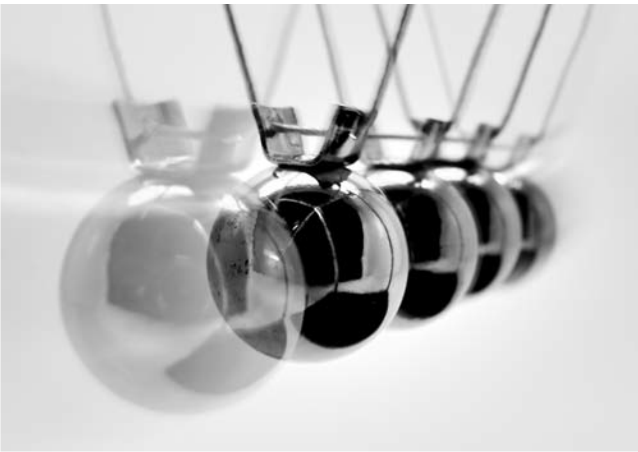
Part III, we reflect on the issues facing the movement now and in the future. To ground these final chapters, we draw on the wisdom of leaders in the movement to share their hopes and dreams for the future.

Many people have supported our journey to create *Impact: Changing the Way We View Disability*. A special thanks to all the consumers across Canada who shared their stories with us. We have been unable to include all the stories in the book, but all the stories we received have been posted on the website of Independent Living Canada (www.ilcanada.ca). We also want to thank the members and leaders who willingly participated in interviews with us. Finally, we express our gratitude to the reviewers who took time to give us feedback on various drafts of the writing: Jihan Abbas, Sandra Carpenter, Charlotte Dingwall, Pam Johnson, Tracy Knutson, Theron Kramer, and Traci Walters.

We trust that this book can serve as an important milestone for this incredible social movement. While there are many hurdles ahead in the desire of people with disabilities to experience full participation and equality, it is important to celebrate the progress and the impact to date.

Christine Malone	John Lord
Project Manager	Principal Writer

PART I



History and Context of a Canadian Innovation

Part I explores issues related to the key historical milestones of the Independent Living movement in Canada and highlights how this movement is unique and innovative in the non-profit sector.

Chapter 1

Independent Living: A Meaningful Social Movement

During the past 25 years, the Independent Living (IL) movement has played a significant role in the way Canadians think and feel about citizens with disabilities. Together with the human rights movement that swept North America in the 1970s and 1980s, the Independent Living movement has gradually enabled Canadians to see people with disabilities as citizens with the same rights as other Canadians. Although many Canadians are unaware of the Independent Living movement, it is likely that most people have been touched by its principles and approaches. Independent Living can be thought of as both a philosophy and a practical approach to living.

As a philosophy, Independent Living stresses that people with disabilities best know their own needs, and should have control over the direction of their own lives. Although this idea seems logical, the reality is that for generations, people with disabilities were expected to be compliant and were often treated as non-persons. Even today, some service systems are designed to take care of people in ways that perpetuate people's dependence and segregation. Full citizenship remains the remotest of possibilities for the clients of such services. As a philosophy, the Independent Living movement promotes values that honour and enhance self-determination and community participation.

Deborah Kennard with Michael Horne

Deborah Kennard from Montreal certainly knows how the Independent Living philosophy can speak to citizens with disabilities. In 1994, Kennard visited the Centre for Independent Living Toronto (CILT) and particularly remembers the other people with disabilities that she met there. "Everywhere I went, people with disabilities knew what they wanted, they weren't afraid to ask for it, they weren't apologetic," she says. Kennard would return to Montreal to study at Dawson College but she wouldn't forget her brush with Independent Living. "It was so wonderful; just so right," she says. Practicing the Independent Living philosophy in her own life has given Kennard the gift of being able to imagine a different and better life. "I have a lot more self-respect than I had ten years ago," she says, "and I'm more aware of possibilities."

Like so many people who have caught the spirit of Independent Living, Deborah Kennard became very involved in this important social movement. She worked tirelessly as a leader during the development of the Montreal Independent Living Resource Centre, and in 2002 was recognized with the Consumer Award of Excellence from the Canadian Association of Independent Living Centres (CAILC).

As a practical approach to living, Independent Living includes a number of principles that reflect the deeper values suggested above. Margaret Wheatley, a leading thinker on social change, says that in complex times such as these, we need simple principles that can guide us. Since its inception in the early 1980s in Canada, the Independent Living movement has understood the power of principles as guideposts for the movement.

Consumer control has always been a fundamental Independent Living principle underlying the deeper values of Independent Living. In essence, consumer control is based on the belief that people with disabilities, like all citizens, should have choice and control over fundamental aspects of their lives. Not surprisingly, in 1980 many service providers and consumers found this principle to be quite radical. In those days, most services available to people with disabilities in their communities were very focused on people's deficits and dominated by medical thinking. Most of these services were quite segregated from community life and focused on "fixing" the person with a disability.

Early leaders of the Independent Living philosophy realized that for most people it would be a significant shift in thinking from a medical mindset to a citizenship mindset. Most services and approaches at the time simply assumed that people with disabilities would continue to be dependent clients of services. The notion of people experiencing full citizenship and participation was only beginning to be considered.

Another important principle of the Independent Living movement is peer support. This age-old principle is based on the belief that experience matters and that people with disabilities can learn a great deal from each other. When the movement was in its infancy, peer support tended to be defined as programmatic, such as peer counselling. Even today, peer support programs continue to be very important for some people, especially newcomers to Independent Living who have had little exposure to possibilities about inclusion and human rights.

Over time, however, the movement realized that peer support is more than a program or a group. It was the late Allan Simpson, long-time managing director of the Winnipeg Independent Living Resource Centre, who coined the phrase "peer support is a methodology." Peer support remains one of the cornerstones of the Independent Living movement, and Independent Living Resource Centres use peer support in the way they interact with people with disabilities who come to the centres for support.

By the 1990s in Canada, peer support was becoming part of everyday language. With its roots in the Independent Living movement, there was finally appreciation for the idea that people who experienced a disability or chronic condition could be a support to people who were new to the experience or who had little experience in community.

The Beginnings of a Social Movement

Some people say that the Independent Living movement in Canada started in 1980 in Winnipeg at the Conference of the International Rehabilitation Congress. At least fifty leaders with disabilities from across Canada attended that conference. They were all part of a fledgling disability movement in Canada, that formerly began in 1976 with the formation of the Coalition of Provincial Organizations of the Handicapped (COPOH), which later became the Council of Canadians with Disabilities (CCD). These activists used this 1980 conference on "Defining the Parameters of Rehabilitation" to broaden their movement and to define Independent Living. They would become the Canadian leaders of the Independent Living movement in Canada.

During this international conference in Winnipeg, the Canadian leaders organized three sessions for delegates with disabilities. More than 200 people from 40 countries attended each session. There was widespread agreement among these delegates that rehabilitation differed from Independent Living. The "sickness" or medical model of rehabilitation was vastly different from the Independent Living approach, which was based on supporting people to live in their chosen communities, rather than warehoused in an asylum or institution. As a symbol of their newly formulated vision to guide their new-found activism, the Canadian leaders handed out buttons that said: "COPOH Consumerism: Partners in Planning and Independent Living."

On Monday evening, June 23, the Winnipeg Conference was abuzz with excitement. Henry Enns, one of the early leaders of COPOH, wrote about that historic meeting years later. Enns recalled that, "Never before in the history of humanity had people with disabilities from all over the world come together to share their experiences." As people began to tell their stories of oppression, exclusion, and rejection, there was a sense of urgency and commitment. Allan Simpson, a Canadian disability movement leader, called out, "Do we want to create an organization of our own?" As Henry Enns remembered, "The resounding 'yes' that came back from every voice in that meeting, could be heard throughout the whole convention centre and was to echo all around the world."[1] Disabled People's International (DPI) was born at this conference. As importantly, Canadian disability leaders realized that their growing commitment to Independent Living was broadly shared by citizens with disabilities around the world. As one leader says, "It gave us confidence to work for change in Canada."

A year earlier, Gerben DeJong, an academic researcher from Boston, had written a significant article entitled, "Independent Living: From Social Movement to Analytic Paradigm." DeJong compared the rehabilitation philosophy with the

Independent Living paradigm, and noted that an Independent Living approach shifted power and control to the consumer, the person with a disability. This article was so important at the time that we have reprinted the essence of it in chart form (*see Table 1*).

The most significant shift in thinking, in addition to the concept of consumer control, was the idea that the problem for people with disabilities was in the environment and the services around them, not within themselves. These two conceptual shifts—consumer control and people not being the problem—made Independent Living radical and very innovative in 1980.

Table 1
Comparison of Rehabilitation and Independent Living Models[2]

Item	Rehabilitation Paradigm	Independent Living Paradigm
Definition of problem	Physical impairment/ lack of vocational skills	Dependence on professionals, relatives, etc.
Locus of problem	Individual	Environment
Solution to problem	Professional intervention by physician, therapist, etc.	Consumer control, peer counselling, self-help, and removal of barriers
Social role	Patient/client	Consumer
Who controls?	Professional	Consumer
Desired outcome	Maximum level and/ or gainful employment	Independent Living

Henry Enns often mentioned how important DeJong's thinking was on the movement in Canada. In fact, Enns' visit to the United States in 1979 convinced him that the time was right for a Canadian version of Independent Living. Later that year he invited DeJong to a Vancouver conference to help Canadian leaders flesh out what a "distinctive Canadian IL approach" might look like. The 1980 Winnipeg conference solidified and broadened the base of support for this idea. Indeed, the consumer voice behind Independent Living was beginning to find a home in Canada.

Fast-forward 25 years and the Independent Living movement now has many locations across Canada. Twenty-eight Independent Living Resource Centres (ILRCs) offer information and networking, provide peer support and skill development opportunities, engage their communities to provide access and inclusion, and challenge our notions of disability through their commitment to self-determination and consumer control.

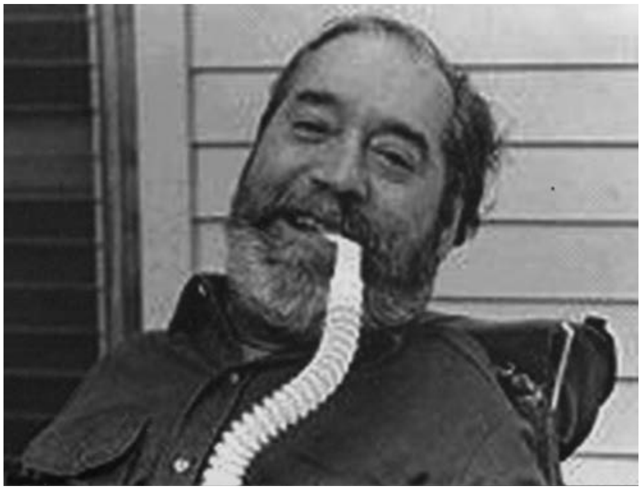
Danielle Lalonde's story is typical of the way these centres support and empower individuals. At about age 40, Lalonde joined the Disability Resource Centre for Independent Living in Kapuskasing, Ontario. Patricia Simone, executive director of the centre, remembers asking Danielle about her dreams and goals. "She...always wanted her drivers' licence," says Simone. "I asked her why she didn't go get one. She stated that she couldn't because all her life she had been told by family members and caseworkers that she couldn't drive and to get that thought out of her mind. I explained to her that, in life, we need to at least try. If she didn't get her drivers' licence, she could at least say she tried," says Simone. The centre matched Lalonde, who has a developmental disability, with a volunteer to study for the written test, while another friend spent time teaching her to drive.

"When they told me I had passed and I had only made two mistakes on the exam, I made them repeat it three times before I actually believed it," reads Danielle Lalonde's autobiography. "I was so excited I started to cry and laugh and I rushed back to the centre to tell them the good news. There was a meeting going on in the drop-in centre and when they saw me, they all started to applaud. I was so happy." Today, Danielle has her own car. Patricia Simone says, "She not only gained independence, but she gained confidence." With this accomplishment, Danielle Lalonde is now working on another dream—to own her own craft store.

Like most social innovation, the growth of the Independent Living movement can be attributed to key people, like Henry Enns, and to relationships and events unfolding at the right time. With this in mind, social movements can in fact help us understand broader social and cultural changes.

Social movements became a significant force in the Western world in the 20th century. The best-known social movement is the civil rights movement, which started in the United States with Martin Luther King and others who were working to change the inequality and oppression experienced by many minority groups. The early stages of a social movement are usually about reframing *what is* to *what could be*. Social movements are thus about possibilities. For people with disabilities, the Independent Living movement has meant moving from being a *client* to being a *citizen*.

The Independent Living movement actually has its roots in the American civil rights movement. Disability movements began to emerge in the late 1960s in tandem with the women's movement, the student movement, and the civil rights movement. People with disabilities began to see disability as a minority concern or political issue, similar to those other movements. All these movements were addressing oppression of one kind or another, and were focusing their efforts for change on issues of social equality. Both the civil rights movement and the women's movement had done extensive research to show that women and people of colour were much more likely to be poor and unemployed than white men. These kinds of statistics struck a chord with leaders in the disability movement in the United States, who knew that citizens with disabilities were experiencing many of the same kinds of barriers. Ed Roberts from California was one of those leaders.


Ed Roberts

Sometimes called the "Father of Independent Living," Ed Roberts was a student at the University of California, Berkley in the 1960s. This was at a time when Berkley was known as the home of radical politics and progressive social movements. Roberts had experienced significant rejection and overprotection in his own life as a person with a disability. He had virtually no functional movement and required a ventilator to breathe. Although the university reluctantly admitted Roberts, he soon became very involved in student politics. Drawing lessons from the other social movements on campus, he started the Independent Living and Disability Rights movement in California. Led by Roberts, students with severe disabilities exerted pressure on the university to become more accessible. This group also sought funds for attendant services on campus. After establishing a resource centre on campus to promote Independent Living, Roberts and others realized the need for a community-based centre.

In 1972, Ed Roberts and a small group of students with disabilities established the community-based Centre for Independent Living in Berkley. Roberts emphasized that independence had to be defined in terms of the control people with disabilities have over their own lives, and not be measured by the tasks one can perform without assistance, as rehabilitation professionals would do. The core values and principles of the Berkley Centre for Independent Living were dignity, peer support, consumer control, civil rights, equal access, integration, and advocacy.

This philosophy of Independent Living took hold very quickly, and by 1975, there were 25 centres across the United States. By 1978, the Rehabilitation Act was amended to include federal funding for centres for Independent Living. Today, there are approximately 400 centres for Independent Living across the United States.

Fraser Valentine, a civil servant with the Canadian government and former staff person with the Canadian Association of Independent Living Centres (CAILC), has completed valuable research on the differences between the American and Canadian movements.[3] Valentine found that while the two movements have similar values and principles, they differ significantly in history and form.

The first difference Valentine notes is what he calls formative influences. While the US movement grew out of the civil rights movement, the Canadian movement, which emerged ten years later, developed from the disability movement and from several interesting alliances, including government and church. The leaders of both movements were predominately young, white males with disabilities. Later in their development, both movements would be criticized by the women's movement. These criticisms will be examined in detail later.

The second difference noted by Valentine was the orientation toward the state. In many ways, the American movement came out of anti-state thinking, even though federal legislation provided funding for centres. Since the welfare state and a social safety net were much more developed in Canada, Valentine says it is not surprising that the Canadian movement is quite connected with the state. This was true in the early years of the IL movement and continues to be the case today, with Independent Living Resource Centres relying heavily on federal and provincial government funding.

Leaders of the Canadian movement have often said that government is a key catalyst for change in how people with disabilities are supported. This approach to the state in fact parallels what Valentine calls "radical liberalism," where the state plays a key role in the voluntary sector by promoting and funding activist citizenship. Whereas US centres are funded through legislation, Canadian centres are in a constant dance with government to ensure that the correct administrative and funding arrangements are in place to support Independent Living Resource Centres.

Table 2 describes the history of the term "consumer." This is the preferred term for describing a person with a disability involved with Independent Living. This history can deepen our understanding of differences and similarities between Canadian and US approaches to Independent Living.

Table 2
History of the Term "Consumer"

Within the Independent Living movement, persons with disabilities are most often referred to as "consumers." Consumer as it is used within the movement is very much linked to the philosophies of social reform inherent to its birth country, the United States. While the disability movement in Britain and Western Europe was shaped by factors such as strong trade unions, a more developed welfare state, and socialist parties, in the United States there was a strong emphasis on civil rights and the free market with its competitive values.[4] Coupled with prevalent American traditions like self-reliance and individualism, disability politics in the US evolved to embrace these ideals. The major "organizational advance" of the disability rights movement was the formation of Independent Living Centres.[5]

Among other unique features of the Independent Living movement outlined by Gerben DeJong, the "consumer metaphor" was fully articulated as integral to the movement.[6] Without a doubt, says DeJong, the movement "broke new ground for disabled people by drawing on the philosophical and political traditions of 'radical consumerism.'"[7] As the Independent Living movement spread to Canada, the idea of the persons with a disability as "consumers" also took hold within the Canadian branch of this movement.

It is important to note that the term "consumer" is not without its critics. For many within the broad disability movement, this terminology places too great an emphasis on the individual in what critics perceive to be a collective struggle, and overestimates the power of the individual within the free market, specifically the power of marginalized groups such as persons with disabilities.

Others note that the term “citizen” more realistically captures the goal and role that people with disabilities desire to play in our society.

Despite criticisms, “consumer” is the preferred term among those connected to and participating in the Canadian movement. Yet, just as Independent Living in Canada has distinguished itself from its American counterpart, “consumer” terminology as well seems to have different meanings and uses among Canadians with disabilities. Indeed, social reform and disability in Canada have been influenced in many ways by factors more similar to their European counterparts. For example, the role and expectations of the government and the influence of collective ideals in public policy are very strong in Canada. As such, the “consumer” in a Canadian context appears to place a greater emphasis on the power to have choice and control in the supports and service process rather than individual purchasing power in a free market.

Innovation and Leadership

Innovators always find their initial reframing grounded in current social realities. Given that people with disabilities had historically been considered *non-persons*, both in law and practice, the reframing to *consumers* and *citizens* challenged medicine, social science, and social work. These professions had contributed heavily to the definition of people with disabilities as “passive” and “deviant.” Social policies that led to the institutionalization of large numbers of people with disabilities also contributed to the perception and social constructions of people with disabilities as “less than human,” “incapable,” and “second-class citizens.” In the early days of the Independent Living movement, these social constructions were challenged and alternatives were presented.

Henry Enns realized that Independent Living could play a significant role in the lives of Canadians with disabilities. This insight was not a research or academic concept for Enns. Like many innovators, he experienced the issue directly and felt compelled to act. In high school and university, Enns had experienced many hospital stays because of worsening arthritis. He also experienced first-hand society’s condescending attitudes toward people with disabilities. By 1974, he became involved with the Manitoba League of the Physically Disabled. As his activism grew, Enns played a leading role in the development of the Independent Living movement in Canada.

Henry Enns

Beginning in 1980, Henry Enns worked for the Mennonite Central Committee for two years and travelled across Canada promoting Independent Living. Toward the end of that journey, Enns wrote in the *Mennonite Reporter*, "An awareness is quietly sweeping the country. It is like a gentle awakening. Like the moving of the Spirit, we see its effects but are not entirely sure where it is going."[8] Enns' comments are typical of innovators, who pursue a dream and seek others who can work with them. They are not attached to outcomes because they focus on process and possibilities. Enns' vision was clear and it would soon resonate across Canada. He reframed the issues in simple yet profound terms: "Emphasis would be on ability rather than disability, on integration rather than segregation, on opportunities and maximum independence rather than dependence on others."

Dave Martin, executive director of the Disability Issues Office of the Province of Manitoba, worked closely with Henry Enns when Martin was active with the Manitoba League of the Physically Disabled. Martin remembers Henry Enns as "a real visionary—he always had big plans. Henry was very good at connecting with people, not only people with disabilities…but government as well, to get funding to support his vision for different projects."

As the Independent Living movement matured through the 1980s, other consumer leaders built on the early vision. Community was stressed as a central adjunct to the core Independent Living philosophies. Sandra Carpenter, a long-time leader from the Centre for Independent Living in Toronto (CILT), wrote in 1988: "The Independent Living movement represents a dream or vision of consumer control and choice within community. Rather than focusing on limitations and dependency on professional interventions, the emphasis is on quality of life and involvement in community…. Independent Living assumes that individuals will become empowered in society."[9] This commitment to community and connections within the wider community deepened as the movement developed.

Also in the 1980s, the general momentum of the disability movement helped enlighten our understanding of disability and the social, cultural, and attitudinal barriers that were preventing full citizenship. For example, during this time, although separate from the Independent Living movement, a related conceptualization of disability began to take hold and challenge existing notions of disability. Referred to as the "social model of disability," it provided academics, policy makers, and the human services field with a paradigm in direct opposition to medical understandings of disability.

As one analyst put it, the social model offered "a new conceptual framework for understanding disability in which it is not the physical, sensory, cognitive, or mental impairment of the individual that disables, but rather disability results from the structural…effects of a society geared towards able-bodiedness as the norm."[10] Indeed, the social model complemented the Independent Living philosophy as a way to shift our collective focus onto those structural and attitudinal areas that create barriers for persons with disabilities. Broad acceptance and understanding of the social model has helped link the oppression and marginalization experienced by persons with disabilities to inequities of existing systems.

Like most innovations, the Independent Living philosophy was at first looked at with suspicion. Several leaders remember that conventional agencies would say either "we already do that" or "why would we want to do that?" Sandra Carpenter points out that this tension still exists in some communities today. The reality is that there is a huge human services industry in Canada that is not consumer driven. Some of this kind of tension is a natural response to innovation, especially since the Independent Living movement proposes a shift in power to those the human service industry has traditionally viewed as "clients." At the same time, many organizations have struggled with change because they either lacked the capacity and resources or were constrained by government policies.

As we shall see, through the 25 years of Independent Living in Canada, this social movement has evolved and continues to evolve. We know from research that social movements and innovations that last have resilience. Frances Westley, a leading researcher on social innovation at the University of Waterloo, says that resilience is the capacity to experience change, while maintaining the integrity of the original.[11] The beginnings of the Independent Living movement started with whispers of possibilities. We have seen those possibilities develop into 28 Independent Living Resource Centres across Canada, with a strong national office, the Canadian Association of Independent Living Centres. Along the way, this movement has experienced huge change, yet still maintains its core principles and integrity. Subsequent chapters explore this journey of change and the resilience of this remarkable movement.

Summary and Reflections

Sometimes social change is attributed to one person or one policy. The reality of social change is usually much more complicated. We can identify several key factors in the development of the Independent Living movement in Canada. Certainly, the frustration and determination of people with disabilities in the 1970s set the stage for leaders to reframe how disability was seen in the culture. However, the Independent Living movement demonstrates that suffering and oppression are not enough to create a movement. As Grace Lee Boggs, a civil rights activist, says, "At the heart of movement building is the concept of two-sided transformation, both of ourselves and of our institutions."[12]

Like other successful social movements, the early leaders in the Independent Living movement understood that people with disabilities could no longer act like victims. They also knew that building the movement would require a clear vision. People with disabilities had a strong desire for change, and Independent Living provided a framework and principles to build such a movement. People such as Henry Enns provided leadership that helped people understand the key principles, and with others, built a uniquely Canadian vision of Independent Living. We can say that Henry Enns, Allan Simpson and other movement leaders learned early on the value of "thinking like a social movement"!

Social movements cannot discount the social forces that impact their work. Some key national and international developments in the early 1980s helped the movement take root. The *Obstacles Report* in 1981 recommended that the federal government fund Independent Living, and put the Canadian government squarely into the world of disability. Subsequently, the government played a vital role in the development of the movement. Without the resources of the federal government, it is hard to imagine how the movement would have matured to the extent it has. Beginning in 1983, the Decade of Disabled Persons, sponsored by the

United Nations, also helped governments and non-governmental organizations focus more deliberately on "full participation and equality."

In a significant way, the Mennonite Central Committee also played a key role by providing resources and support to the two original centres: Kitchener and Winnipeg. As we shall see, this partnership building was central to the first two centres, and became a key strategy in the development and growth of future Independent Living Resource Centres.

Table 3 summarizes the key factors in the development of the Independent Living movement in Canada.

Table 3
Key Factors in the Development of the Canadian Independent Living Movement

1. In the 1970s, many people with disabilities were tired of compliance and began organizing for change, including starting the Coalition of Provincial Organizations of the Handicapped, now called the Council of Canadians with Disabilities.
2. Human rights movements, the civil rights movement, and the women's movement all influenced the culture of North America and helped prepare the ground for a specific rights movement related to disability and Independent Living.
3. Leaders with disabilities were reframing disability from an individual problem (medical issue) to a social problem (need to remove barriers).
4. The American IL movement was underway and literature from its success was available to Canadian leaders.
5. The deinstitutionalization movement was underway and both federal and provincial governments were looking for alternatives to institutionalization.
6. The Canadian government's *Obstacles Report* in 1981 highlighted issues facing people with disabilities and made important recommendations for change. The UN Decade of Disabled Persons (1983–1992) also provided a focus for full participation and citizenship.
7. Henry Enns' leadership was a catalyst for starting the first two Independent Living Resource Centres, which became an expression of the movement.

8. The Mennonite Central Committee supported the IL movement with Henry Enns' time, as well as resources, to start two centres in Kitchener and Winnipeg.

New social movements reflect new paradigms that are grounded in concepts of equality, citizenship, human rights, quality of life, and inclusion. This is the language of the Independent Living movement. The voice of Canadians with disabilities remains strong in this movement through two channels. The first channel is the national organization, the Canadian Association of Independent Living Centres (CAILC), now called Independent Living Canada, which supports local affiliates, works on policy issues, develops innovative projects in collaboration with national partners and its member centres, and sponsors and conducts research.

The other channel is the Independent Living Resource Centres (ILRC), which have become the local voice of the Independent Living movement. As such, they play a vital role as a community structure for people with disabilities across Canada—a structure that welcomes and supports each person's dreams and hopes for a full life in community. Centres are facilitators of partnerships and act as a local hub of cross-disability information and supports. The focus of these local centres is mostly on listening, peer support, skill development, individual advocacy, community development, and personalized supports. We now know that these functions can be very empowering when done well within an Independent Living philosophy based on strong values and clear principles.

In a sense, the presence of an Independent Living Centre enhances options and meaning for citizens with disabilities and the communities in which they are located. The cross-Canada Independent Living movement grounds this local work in sustaining values and principles.

> *Your playing small does not serve the world. There's nothing enlightened about shrinking so that other people won't feel insecure around you. We are all meant to shine... It is not just in some of us; it is in everyone. And as we let our own light shine, we unconsciously give other people permission to do the same. As we are liberated from our own fear, our presence automatically liberates others.*
>
> —Marianne Williamson, *A Return to Love*

Endnotes

1 Henry Enns and Yutta Fricke, "The Emergence of a Global Disability Rights Movement," in *In Pursuit of Equal Participation: Canada and Disability at Home and Abroad,* eds. Henry Enns and Aldred Neufeldt (Toronto: Captus Press, 2003), 84–85.

2 This chart is from Gerben DeJong, "Independent Living: From Social Movement to Analytic Paradigm," *Archives of Physical Medicine and Rehabilitation*, 60, no. 10 (October 1979): 443.

3 See two documents written by Fraser Valentine. The first was an historical overview and the second an analysis of disability movements in Canada, with some reference to the United States: *The Canadian Independent Living Movement: An Historical Overview* (Ottawa: Canadian Association of Independent Living Centres, 1994); *Locating Disability: People with Disabilities, Their Movements, and the Canadian Federal State* (Master's thesis, Carleton University, 1996).

4 T. Shakespeare and N. Watson, "Making the Difference: Disability, Politics, and Recognition," in *Handbook of Disability Studies,* eds. G. Albrecht, K. Seelman, and M. Bury (London: Sage Publications, 2001), 546– 564. Also see Michael Oliver, *The Politics of Disablement* (London: Macmillan, 1990).

5 Shakespeare and Watson, ibid.

6 Gerben DeJong, "Independent Living: From Social Movement to Analytical Paradigm," *Archives of Physical Medicine and Rehabilitation*. 60, no. 10 (1979):435–446.

7 Ibid, 437.

8 Henry Enns, "Independent Living," *Mennonite Reporter,* 11 (2), January 19, 1981.

9 Sandra Carpenter, *The Centre for Independent Living in Toronto: An Overview* (Toronto: CILT, 1988).

10 G. Hughes, "A Suitable Case for Treatment? Construction of Disability," in *Embodying the Social: Constructions of Difference,* ed. E. Saraga (London: Routledge, 1998).

11 Frances Westley, Brenda Zimmerman, and Michael Quinn Patton, *Getting to Maybe: How the World Is Changed* (Toronto: Random House Canada, 2006).

12 Grace Lee Boggs, "Seven Great Ideas for Movement Leaders," *Michigan Citizen*, February 20, 2005. This article and other resources on social movements are available at Tamarack: An Institute for Community Engagement [www.tamarackcommunity.ca].

Chapter 2

Redefining Disability and Independent Living: Tentative First Steps

She is deaf. He is paraplegic. Disability is often viewed as a permanent status. In reality, disability is a relationship between a person with an impairment and their social and physical environment. In this sense, we can say that disability is socially constructed. This means that over time, people and cultures create meaning about disability. The reality is that for a long time disability has been defined as subordinate and deficit oriented. In our Western culture, the roles of people with disabilities as clients or as compliant are assumed to be a natural consequence of disability, and have been learned by people with and without disabilities.

The consequences of being labelled disabled have been enormous for Canadians with disabilities. Citizens with disabilities have been institutionalized at very high rates, and employment and educational attainment data reflect this marginalization. For example, among persons with disabilities the employment rate for men is 41 percent and 32 percent for women, while the employment rates for their non-disabled peers are 83 percent for men and 70 percent for women.[1] With this in mind, it is not surprising that poverty is far more common among people with disabilities than it is for the general population, with 41 percent of those using food banks in the Toronto area having either a disability or long-term illness.[2] Across

Canada, persons with disabilities also remain more likely to experience food insecurity (to go without food, eat less, and be unable to purchase needed food).[3] Recent research shows that people who have experienced a major mental illness die 20 to 25 years younger than do other Canadians, not because of the mental illness, but because of other factors such as poor medical care and poverty.[4]

The Movement to Redefine "Disability"

The life experiences of people with disabilities are dramatically different from other Canadians. In a recent summary of those differences, Canadian researchers identify six ways in which in the social construction of disability has led to compliance and clienthood:

- **The segregation of people** with labels and differences;
- **The control of services** by professionalized agencies, rather than by people and their networks;
- **The continuum of services**, which assumes that people with disabilities must go through many steps before they can participate fully in community life;
- **Limited participation** in organizational governance and decision making;
- **Lack of person-centred approaches** that fully support self-determination and community participation; and
- **Social service cutbacks**.

These researchers point out that traditional practices have led to rotten outcomes for people with disabilities, including a great deal of community institutionalization, poverty and high unemployment, health-related problems, high degrees of abuse, and weak social networks.[5]

In the 1970s, this kind of analysis fuelled the Canadian disability movement to redefine disability. As we have seen, disability leaders were frustrated with traditional services and rehabilitation that offered few choices and limited control to consumers. Allan Simpson, long-time managing director of the Winnipeg Independent Living Resource Centre and one of the most articulate leaders in the 1970s, often said that if people with disabilities had the same rights as everyone else, then real options could begin to take hold. As the conversations grew among leaders in the disability movement, they increasingly found that "Independent Living" was an idea that made sense as part of the work to redefine disability.

While the broader disability movement was working to redefine disability, the Independent Living movement was building momentum to contribute to this work in substantive ways. From its inception, the Independent Living movement has worked to redefine disability in practice. Changing power relationships was central to this work. When Henry Enns was speaking across Canada about Independent Living, he emphasized the need for people with disabilities to experience what could be called "consumer control." Consumer control, although not well articulated, was based on the observation that as children grow and develop, they increase their autonomy and independence. As Sandra Carpenter from the Centre for Independent Living Toronto, points out, "'Consumer control' was an important piece for a person with a disability to gain mastery or control of their bodies and environment."

Furthermore, in the early 1980s, the focus was on developing Independent Living Resource Centres that were consistent with the principles and values of IL, and designed to assist people to shift power relationships dramatically. People with disabilities would be in charge and would make decisions about the direction of their lives and the day-to-day workings of the centres. Independent Living Resource Centres were seen as a vehicle to build skills and confidence of individuals, so they could take their rightful place in society.

As the fledgling Independent Living movement was exploring how to redefine disability, leaders understood the power of the environment in shaping people's experience. Access was a critical issue in those early days. People realized that when the social and physical environments are welcoming and accessible, people had a much greater chance of being included. When people are included for their gifts and strengths, their disability has less impact on their participation. The meaning of disability changes as we think about people participating and contributing in families, neighbourhoods, workplaces, and the wider community. As the broader disability movement began to redefine disability, rights and participation were central ideas. In addition, the meaning of independence was increasingly seen as an important part of redefining disability.

As outlined in Table 4, the definition of "Independent Living" is often misunderstood, and continues to be a challenge even today.

Table 4
The Challenge of Understanding "Independent Living"

"Independent Living" has been a difficult phrase for people to understand and live by. Irving Zola, a leader of the American movement, pointed out in 1982 that, "Independence is not measured by the mundane physical tasks we can do but by the personal and economic decisions we can make. It is not the quantity of tasks we can perform, but the quality of life we can live with help."[6] Independent Living, then, must include physical, social, and psychological well-being defined by the person. No matter what the disability label, people can make choices, and can be citizens and participants, with whatever support they may require. The Independent Living movement's definition of disability and independence remains a challenge to rehabilitation and social service systems, many of which continue to tie people's potential for independence to physical or cognitive ability.

Jim Derksen, a leader within the Council of Canadians with Disabilities, wrote in 1983 that many people were confusing Independent Living with a new idea for housing people with disabilities or with the provision of attendant services. Derksen pointed out that "… [though] such ideas about housing and attendant services may be important in working toward full participation for disabled people, they are really not the centre of the IL concept." Rather, wrote Derksen, "The Independent Living concept at its heart has to do with the self-determination and liberation for the individual within his society through collective self-determination and self-help…"[7]

Cathy LaFrance, former executive director of the Duncan Centre in British Columbia, recalls the differences between traditional services and the Independent Living approach. LaFrance worked in group homes where people's lives were quite controlled. After reading about Independent Living, she left her traditional agency and became part of the founding group of the Duncan Centre. Even in small group homes, LaFrance says, "there was lots of regimented kind of living styles, where the menus were set for residents, there was a curfew, and people's meds were handed out to them." LaFrance notes that her own personal values were always in conflict with what she was being asked to do at work.

In contrast, LaFrance found the Independent Living principles very empowering. She explains that the process of shifting power to the person and to organizations is vital. In reflecting on the Duncan Centre, she says, "From our vision statement, to our mission statement, through our programs and services, and right through to how we delivered service, these IL principles were the foundation that we worked from at all times. Whenever there was a question of whether we should be doing something or not, we always went back to those IL principles."

Cathy LaFrance

What are these IL principles and how did they become so important in the movement to redefine disability? (*see Table 5*). How did those tentative first steps become the foundation for a significant social change movement?

A Growing Consensus

By 1981, there was a broad consensus among disability activists that one important way to redefine disability in Canada was through the development of Independent Living Resource Centres. This recognition did not reduce the importance of other components of the redefinition of disability. Equal rights and full participation were also central to any new conceptions of disability. Independent Living Resource Centres were seen as the vehicle for the expression of these values.

The Coalition of Provincial Organizations of the Handicapped (COPOH), later to become the Council of Canadians with Disabilities, had many discussions about Independent Living. At first, many people felt that the Independent Living approach could be part of COPOH and the disability consumer movement. Gradually, under the leadership of Henry Enns and Allan Simpson, COPOH came to understand that Independent Living Resource Centres needed their own identity in which to grow and develop. Because of this thinking, COPOH established an Independent Living Committee.

Some leaders say that this COPOH committee was instrumental in designing the Canadian Independent Living movement in ways that were distinct from the

American movement. One defining characteristic that the COPOH committee recommended was to separate individual or self-advocacy from collective or systemic advocacy. Centres for Independent Living in the US entwine both service delivery and collective advocacy. The COPOH committee thought it made more sense for the disability consumer movement, including COPOH, to be responsible for collective advocacy and lobbying for change. Independent Living Resource Centres, they concluded, should focus on information sharing and the development of personal empowerment skills, while being responsive to individual/self-advocacy concerns.

Traci Walters, national director of CAILC since 1993, expresses even more emphatically the role and mission of Independent Living Resource Centres. Walters says, "The IL movement provides, at the grassroots level, an individualized, responsive, consumer-oriented approach to the exercise of citizenship rights and the empowerment of individuals with disabilities."[8]

Pat Pardo, former executive director of the Calgary Centre, reflects on this early period of consensus building among disability leaders,[9] noting there was a struggle to figure out which of the several models or frameworks made sense. Academic research, such as the work of Gerben DeJong, was instrumental in shaping people's views on disability. Consumer leaders found that the socio-political model made most sense. Pat Pardo notes that, "The socio-political model differs from the other two (bio-medical and economic) in that the problem is not in the disability, but with the attitudinal, environmental, and systemic obstacles imposed upon people with a disability." For Pardo and other disability leaders, the insight that disability was in fact socially constructed simply reinforced their personal experience. Furthermore, they reasoned, if disability has been constructed in a certain way, then couldn't we reconstruct or redefine disability? Wouldn't Independent Living Resource Centres, developed and operated by people with disabilities, advance our thinking and possibilities?

As the movement began to develop Independent Living Resource Centres, a definition emerged from the Canadian Association that captured a new spirit of the empowerment and possibilities of citizens with disabilities:

> **Independent Living Resource Centres promote and enable the progressive process of citizens with disabilities to take the responsibility for the development and management of personal and community resources.[10]**

People with disabilities were now to be seen, not as victims or clients, but as responsible leaders. One way to shift power to citizens with disabilities was to ensure they had control over resources designated to support them, usually by government with the direction of service providers.

This definition of an Independent Living Centre was accompanied by six guiding principles *(see Table 5)*. These principles express the redefinition of disability emerging from the disability movement: that disability is socially constructed; that people with impairments have the same rights as other Canadians; and that full participation is central to people with disabilities experiencing full citizenship.

Key Principles of Independent Living

The initial principles of the Independent Living movement are as relevant today as they were in the early 1980s. This in itself is quite remarkable, considering that the movement has matured in some significant ways over the last 25 years. What has changed during this time is the awareness of how the principles can best be implemented. These insights have emerged from centre initiatives, from various research and evaluation projects, and from lessons learned by leaders and practitioners. The original key principles of Independent Living are outlined in Table 5. For each principle, the underlying value is described. We can think of these value statements as more universal beliefs than the principles.

Table 5
Original Key Principles of Independent Living

Consumer Control: Independent Living Resource Centres are consumer controlled. Decisions about directions and implementation are made by people with disabilities. The majority of board members are people with disabilities. This principle of consumer control and self-determination guides the work carried out with people who use centres.

Underlying value: Control over one’s environment is critical to developing capacity for self-determination and for being recognized as a fully capable, autonomous human being.

Cross-Disability: Centre programs are designed to respond to the needs of all citizens with a disability. Fundamental to this principle is the idea that all people with disabilities have the right to make choices, make mistakes, and take responsibility for their own lives.

Underlying value: People with disabilities, no matter what the specific disability, have a common struggle for equality. There is a universality to disability issues.

Community Based: Centres are based in their communities, and respond to local needs and issues as identified by local citizens. This community development approach applies to service development, evaluation, and promotion. Programs and services are designed to complement existing community resources and services.

Underlying value: Community is the place for all citizens. People with disabilities benefit from and contribute to their communities and society.

Peer Support*:* Centres base their work on peer support and mutual learning among people with disabilities. Centres promote the philosophy and practice of peer support, often with staff or volunteers as peer mentors or peer group leaders.

Underlying value: People with similar experiences can support each other and learn from each other's successes and failures. This support contributes to a positive sense of self.

Integration and Full Participation: Centres promote the involvement of citizens with disabilities in all aspects of community life. Centres provide consumers with tools, support, resources, self-confidence, and self-management skills that enable people to achieve personal goals.

Underlying value: Inclusion and integration enhance the full range of social participation. Full participation means that people with disabilities experience their gifts and strengths in community fully.

Non-Profit: Centres are non-profit enterprises, with a board of directors and members who are committed to alternatives to existing service provision. Centres form partnerships with community groups.

Underlying value: A profit motive or market-driven model contradicts the goals of Independent Living movement. Non-profit status insures that people with disabilities can have governance responsibilities as board members and leaders.

Although the Independent Living principles have stood the test of time, our understanding of them has deepened. Some principles have benefited from research, while others have changed their emphasis somewhat over the years in response to feedback from consumers and centres. The principle of consumer control, for example, now has an extensive body of literature on self-determination.[11] In recent years, self-determination has emerged as a key value and principle. Sometimes it goes by different names, such as "recovery" in community mental health, or "person-centred" in work done with individuals with developmental disabilities.

Sandra Carpenter (left), Audrey King and Bev Elliot at the Centre for Independent Living in Toronto, AGM 2008

Consumer control, including self-determination, is seen by many as *the* key principle, because it clearly shifts power to the person and to the Independent Living organization. Sandra Carpenter from the Toronto Centre notes there is a difference between *consumer-controlled* and *consumer-centered*. She stresses the importance of consumer *control*, which must include the governance and operation of organizations. Carpenter notes that it should be about "people doing it for themselves."

Self-determination and consumer control have very specific meanings within the Independent Living movement. Rene Gadacz has written that self-determination for people with disabilities is often the process by which new identities are formed.[12] Gadacz argues that this means people must often become involved in a process of relearning that involves breaking away from previous definitions of disability and of self. Opportunities for self-determination create a window for both personal growth and social involvement. As people begin to make their own choices and increase responsibility for those choices, it changes their interactions with the world. Allan Simpson used to say that, with an Independent Living approach, the means of addressing goals and issues was as important as the outcomes themselves. This idea honours the person and their process.

Consumer control and self-determination are intricately linked to community participation, because people's desire to express themselves inevitably moves them to begin negotiating with the wider world. This leads the Independent Living movement directly to the principle of integration into the wider society. The integration and full participation principle today might be called social inclusion. Inclusion, of course, has a broader meaning than integration, and recognizes that being *in* the community is not enough, and that people desire to be active citizens *of* the community. Sandra Carpenter has conceptualized this as "integration *plus* accommodation *equals* inclusion." Full participation has long been an Independent Living goal and it affirms that citizenship includes involvement *as well as* appropriate accommodations and individualized approaches. These accommodations are now seen as important inclusion supports. Independent Living Resource Centres support people in learning how to negotiate their social worlds, which include non-disabled people and social structures.

Paula Saunders, long-time staff person with Waterloo Region Independent Living Centre, reflects on this principle in terms of change and the redefinition of disability. "It is important that we continue with change because our world is changing," says Saunders. "I think we maybe should not always use the disability card as a stopper. We have to hope that people are looking at us as people and not just at the disability." Saunders adds, "That's the big thing that I learned from Henry Enns: that I'm a person first, my disability is second. This means, as a person I want 'this,' and as a person with a disability I will do it 'this' way." Saunders' description is a powerful metaphor for thinking about equality and accommodation.

As outlined in the previous chapter, the peer support principle is also fundamental to the Independent Living movement. *Learning from each other* builds on the mutual aid idea that people with similar issues or experiences can learn from each other's experience. Given the professional and service world that many people with disabilities experience, peer support also reiterates that disability issues are not synonymous with professional intervention.

The cross-disability principle of Independent Living Resource Centres recognizes that anyone with a disability can benefit from this new philosophy. In some ways, citizens with complex disabilities stand to benefit most from this principle.

The birth of the movement in the United States occurred in part because of the anomaly of people with significant disabilities. Remember Ed Roberts from California? By example, Roberts and others with significant disabilities showed that they could live in the community, despite the best intentions of rehabilitation. This anomaly provided the impetus for Roberts and others to start a community-based Independent Living Centre.

The cross-disability principle makes sense in theory, but it has been challenging to implement. Cross-disability means that staff people need to be comfortable with a range of disabilities. And it means that people with significant disabilities are welcomed as members and leaders. It also means that all citizens with disabilities can experience the dignity of risk, an important idea that is often overlooked with people with significant disabilities.

Independent Living Resource Centres have always been non-profit, and this was seen as a foundational principle. The early leaders believed that the lives of people with disabilities should not be at the whim of the marketplace. Non-profit centres with boards of directors also provide an important community safeguard. It was also felt that accountability would be increased by having people with disabilities making up more than 50 percent of the boards.

The essence of each of these six principles created a paradigm shift in the way disability movements were defining disability. Regardless of people's impairments, they are seen as capable of making self-determined choices. Regardless of the degree of disability, people are seen as having a right to participate in the community and are important to the overall life and vitality of the community. Regardless of people's experience, they can benefit from peer support. All of these ideas have their roots in the Independent Living movement.

People who are active in the Independent Living movement speak eloquently about the principles and the paradigm shift that it represents. People typically refer to consumer control as a touchstone principle. And yet, other principles are also seen as central. Perhaps what is most interesting is how people see the connection among all the principles. Michael Horne, long-time staff person with the Niagara Centre and former CAILC staff member, describes the principles as guidelines for action for individuals and organizations. "Living the principles daily in an Independent Living Centre grounds people in important and real issues," says Horne. "My years of work at the Niagara Centre were more valuable than any college education. When someone walks through the door of an ILRC with multiple challenges, it brings you to the deeper systemic issues that people face. The Independent Living principles genuinely help at both the individual and collective levels."

As we shall see, when members of Independent Living Resource Centres tell their stories, they often refer to these principles. As individuals move through their life journey, they seem to take on the principles that matter most to them and make them their own.

The Canadian Association of Independent Living Centres has been instrumental over the years in facilitating think tanks that bring people together to reflect on a particular principle as a community of practice. All the peer support staff across Canada, for example, might come together to reflect on their work. These intentional spaces for reflection create time to take stock, to share ideas, build capacity, and to ponder how to stay true to the principles in daily life.

Mike Murphy is typical of the leaders who have grown with the movement. As executive director of the Kingston Centre, he continually revisits the Independent Living principles. "The Independent Living lens," says Murphy, "requires that we continually challenge ourselves in terms of what the Independent Living principles mean for ourselves and our organizations." Murphy learned the principles through a kind of mentoring process. He remembers following Allan Simpson and Henry Enns "around like a puppy dog." Murphy is now a mentor for his staff and others; he constantly urges them to look at all programs and projects through an Independent Living lens that is framed with the key principles.

Partnerships with Community and Government

By late 1981, interest in Independent Living was growing. The leaders of the movement recognized that people with disabilities would not be able to change society's definition of disability or create a network of Independent Living Resource Centres without support from other sectors of society. The COPOH Committee on Independent Living was actively promoting the Independent Living philosophy in the disability movement and had begun to talk with federal government officials about their ideas. When speaking across Canada, Henry Enns built relationships with leaders in the disability movement, civil servants, and politicians at the federal level of government, as well as leaders in the Mennonite Church of Canada.

The Mennonite Church has long been committed to social justice. Enns' involvement in the church in Manitoba had helped him understand the biblical basis of social justice. When the Mennonite Central Committee agreed to fund Enns for two years to build awareness across Canada, they were planting seeds for the Independent Living movement. As part of that journey, Enns would meet Ontario Mennonite Central Committee leaders in Kitchener–Waterloo. This meeting would eventually result in the first Independent Living Centre in Canada.

The federal government released its *Obstacles Report* in 1981, highlighting numerous issues facing Canadians with disabilities. In many ways, this was a remarkable report, showing both the struggles and resilience of people with disabilities. The report, based on the work of seven Members of Parliament on a special parliamentary committee, also presented detailed policy directions in every area of life for people with disabilities. Released during the International Year of Disabled Persons, this report provided impetus for the federal government to support the fledgling Independent Living movement. One of the recommendations of the *Obstacles Report* was to "establish funds for demonstration projects in Independent Living."

The Secretary of State in the Federal Government was charged with implementing some of the recommendations of the *Obstacles Report*. Henry Enns and other leaders met with the civil servants in 1982, and indicated how important it was to fund some Independent Living initiatives. At the same time, Enns began working with groups in Kitchener–Waterloo and Winnipeg to create the first Centres for Independent Living in Canada.

The First Centre: Kitchener–Waterloo Steps Up

When Henry Enns first visited Kitchener in 1981, he met with Ray Schlegel, executive director of the Mennonite Central Committee (MCC). The MCC at the time was in the midst of a growth period and was looking for broader involvements in Southwestern Ontario. When Henry Enns asked MCC to consider starting an Independent Living Centre, Schlegel and MCC were enthusiastic and formed a task force to study its feasibility.

Gary Nyp, a journalist from Waterloo Region, wrote about the development of the Kitchener Centre in his 2002 book, *Reaching for More: The Evolution of the Independent Living Centre of Waterloo Region*. In recounting the early work in Kitchener, Nyp credits Henry Enns with having the vision. As a visionary, he made others on the task force aware of the issues and the fact that they were talking about a paradigm shift. While MCC had stepped up with support and funds, other community members also took on leadership roles. Brice Balmer, a local chaplain within a large community organization, became chair of the initial committee. Balmer, deeply committed to social justice, played a significant role in keeping the centre on track in those early days.

With seed money from MCC and a small grant from the Federal Government's Secretary of State, the Kitchener Centre hired two women with disabilities who carried out the initial work to determine community needs and interests. This needs assessment showed that many people with disabilities were interested in a centre, and that affordable, accessible housing was a vital issue in the community. Based on the findings of this research, the centre was born and housing became its first priority. Henry Enns became the first executive director and lived in Kitchener for a year. A $54,000 grant was obtained from the Secretary of State to fund the operations, and the Mennonite Central Committee continued its funding and support role. When the centre officially opened in September of 1982, it consisted of four staff people. Twenty years later in the fall of 2002, the Kitchener Centre boasted an annual budget of over $5 million, including four housing projects, an extensive range of individualized, consumer-directed attendant services, and many of the usual Independent Living functions, such as peer support, information and networking, and individual advocacy.

Traci Walters, national director of CAILC since 1993, often refers to the Kitchener–Waterloo Centre as a "beacon." As the first centre, it became a model for others and in very practical ways helped to redefine disability through Independent Living.

Winnipeg: A Natural Alliance

The city of Winnipeg has long been steeped in disability activism and has been the home of the Council of Canadians with Disabilities (formerly COPOH) and Disabled Person's International (DPI). As well, the Manitoba League for the Physically Handicapped was very active in Winnipeg in the 1980s and the Mennonite Central Committee played a key role in disability issues. Henry Enns knew that Winnipeg would be a natural alliance for the Independent Living movement.

The Mennonite Central Committee (MCC) in Winnipeg had established the Handicapped Concerns Committee in 1980 that had begun to explore how MCC could best impact disability issues in the region. By early 1982, a Steering Committee on Independent Living was formed, chaired by Diane Dreidger, a volunteer with MCC. With representation from MCC and the Manitoba League, the Steering Committee took time to sort out their vision. According to Dreidger, Henry Enns once again became the "direction finder." Although few people really knew what Independent Living was at the time, other leaders worked with Enns to advance a clear agenda. Jim Derksen, a long-time disability activist and leader in the movement, and David Martin from the Manitoba League were already living the philosophy and helped propel the committee forward.

In the summer of 1983, a research grant enabled the Steering Committee to study the feasibility of an Independent Living Centre in Winnipeg. Several meetings were held that summer with citizens with disabilities. It soon became clear that people wanted something different from the Manitoba Society for Crippled Children and Adults, which at the time had a monopoly on services and supports. Results of the feasibility study showed the need for an Independent Living Centre that would address peer support, networking, information, and individual advocacy.

When the Winnipeg Independent Living Centre opened in February 1984, Henry Enns was once again the acting director, with three other staff, including two MCC volunteers. Initial funding came from a small grant obtained through Canada Employment and Immigration, with continued MCC financial and human resource support. Winnipeg built upon the Kitchener–Waterloo experience of consumer direction and control. It also advanced the Independent Living approach by emphasizing from the beginning that the centre would provide support and individual advocacy, while the Manitoba League would provide collective advocacy. This initially was the practical way that the disability movement addressed these separate functions in the way supports are provided to people with disabilities. As we shall see, over the years, this idea of

Allan Simpson shaking hands with Prime Minister Jean Chrétien

various functions, rather than service monopolies, has become an important part of the new paradigm.

In late 1984, Allan Simpson, who had been a leader with both COPOH and the Manitoba League, found himself in a fortuitous position. Trained in actuary mathematics, the insurance company he worked for was sold. Almost immediately, Simpson was hired to be the managing director of the Winnipeg Centre. According to family and friends who knew him, Simpson had lived the philosophy of IL since he contracted polio at age 14. He was an incessant questioner, and many colleagues recall late-night conversations with him about Independent Living. Simpson was passionate about the value of Independent Living, and over the next fifteen years as managing director of the Winnipeg Centre, he was able to build dozens of partnerships with all three levels of government, several foundations, and the business community. By the late 1980s, it was well known that the Winnipeg Centre was thriving and often the envy of other centres across Canada. Much of that capacity-building work can be attributed to the leadership of Allan Simpson.

Summary and Reflections

In the early stages of a social movement, a tone is sometimes set for what will follow. From the early days, the Independent Living movement in Canada understood the importance of partnerships. This early commitment to partnering with allies who could advance the IL agenda turned out to be an important strategic decision. Henry Enns and Allan Simpson were both master partnership builders. As we shall explore, the strength of these partnerships is reflected today in centres across Canada.

By setting a positive example for what was to follow, the first two Independent Living Resource Centres also gave life to new definitions of disability. Consumers in Winnipeg and Kitchener recall the resistance and sometimes disdain that came from other professionals when they first heard about the Independent Living approach. Brice Balmer from Kitchener describes the professional planning system as "patriarchal" and several people use the phrase "condescending" when describing early resistance to an IL approach.

Leaders in Kitchener–Waterloo and Winnipeg had to be persistent to get their centres off the ground. Putting in place a centre that works from Independent Living principles began to demonstrate that people with disabilities can take control of their own lives. This early work in grounding the philosophy in day-to-day practice gradually created welcoming resource centres for people with disabilities in their own communities. At the same time, early centres inspired others across Canada about how Independent Living could be viable in their communities. Table 6 summarizes the conditions that helped redefine disability in Canada and the key role that Independent Living played in this history.

Table 6
Conditions That Helped Redefine Disability:
The Role of Independent Living

---

1. The Independent Living Committee of the Coalition of Provincial Organizations of the Handicapped raised awareness about IL with its member organizations and with government. National leaders played a key role in presenting new ways of seeing disability and providing a vision for Independent Living in Canada.
2. The influence of the social model of disability, consistent with an IL approach, was a direct challenge to the dominance of the medical model. Governments and non-governmental organizations were beginning to understand these differences.
3. The six Independent Living principles resonated with the lives of people with disabilities and made sense to communities that were considering the development centres.
4. The principles and their underlying values provided the IL movement with a sound direction and clear alternative to existing approaches at the time.

5. Local leaders and activists helped build momentum for a new definition of disability, while garnering support and status for emerging local centres.
6. Involving previously excluded people in local work validated the IL principles and increased the credibility of this young social movement.
7. Genuine partnerships between centres, other local organizations, and the federal government created alliances based on understanding and support for the new definition of disability.

Local leaders and activists have always been the heart of any social movement. While national leaders frame the vision, local people act on the vision in practical ways that make sense to their fellow citizens. Local leaders also give momentum to new ideas. Such was the leadership of Jim Derksen and David Martin in Winnipeg, and Brice Balmer and Helen McMichael in Kitchener. As the first person with a disability hired in the Kitchener centre, McMichael worked tirelessly in reaching out to consumers in her community. Many remember Helen McMichael as a woman who was passionate about the need for a new paradigm. Few people actually knew that McMichael had been forced to live in a nursing home for years. She was dedicated to ensuring that no one in future generations would have to experience that fate.

This commitment to a cause often typifies community leaders and activists in social movements. From these tentative first steps in Kitchener–Waterloo and Winnipeg, what is remarkable is how many similar leaders with and without disabilities have stepped up in other communities across Canada.

> *People with disabilities have enormous gifts to contribute to society when we are fully included, supported and welcomed to participate and lead. We have come to value diversity…as the very essence of our lives. While others may see us as deficient or broken, we see ourselves as different—deliciously different. Our variety challenges dull standards of uniformity, false notions of perfection. Difference means options to explore…. We know how to adapt. We know and appreciate and embrace our own differences and those of our friends.*
>
> —Bonnie Sherr Klein, Canadian filmmaker and disability activist, author of *Slow Dance*

Endnotes

1 Government of Canada, *Advancing the Inclusion of Persons with Disabilities* (Ottawa: Human Resources Development Canada, 2002).

2 United Way of Greater Toronto, *United Way Facts: Helping People with Disabilities Live Independently,* 2002.

3 Canadian Council on Social Development, *Disability Information Sheet # 10,* Ottawa, Ontario, 2003.

4 Andre Picard, "We Can't Sacrifice the Body in Treating Mental Illnesses," *Globe and Mail*, October 18, 2007: L 10.

5 John Lord and Peggy Hutchison, *Pathways to Inclusion: Building a New Story with People and Communities* (Toronto: Captus Press, 2007).

6 Irving Zola was a professor at Brandeis University in Boston and a leader in the early days of the American Independent Living movement. As a person with a disability, his writings have strong personal dimensions alongside his professional insights. See Irving Zola, *Disincentives to Independent Living*, Monograph # 1, Research and Training Center on Independent Living (Lawrence, KS: University of Kansas, 1982), 4.

7 Jim Derksen, *The Independent Living Movement and the Self-Help Process*. Paper presented to Disabled People's International, Bangkok, Thailand (April), 1983: 7.

8 Traci Walters, "Approaching a New Stage of Empowerment," *Abilities* (Summer 1997): 36–37.

9 Patricia Pardo, *Independent Living: An Ideology or Just Another Service Delivery Model?* (Ottawa: Canadian Association of Independent Living Centres, no date).

10 CAILC, *Definitions: Background Paper* (Ottawa: Canadian Association of Independent Living Centres, 1985).

11 For a deeper exploration of self-determination, see John Lord and Peggy Hutchison, *Pathways to Inclusion*. Also see Michael Wehmeyer, "Self-Determination and Individuals with Significant Disabilities: Examining Meanings and Misinterpretations," *Research and Practice for Persons with Severe Disabilities* 23, no. 1 (1998): 5–16. The Center for Self-Determination in the United States also produces some interesting resources and holds conferences on self-determination. Their website is [www.self-determination.com].

12 Rene Gadacz, *Re-Thinking Disability: New Structures, New Relationships* (Edmonton: University of Alberta Press, 1994).

Chapter 3

Independent Living Resource Centres: Unique Leaders in the Non-Profit Sector

At the 2006 Annual General Meeting of the Canadian Association of Independent Living Centres (CAILC), Board Chair Paul-Claude Bérubé spoke about the maturing of the Independent Living movement. Using the metaphor of a train, Bérubé explained that, "Each time we add a new Independent Living Resource Centre to our train, we become stronger as a movement." In 1982, the first centre opened in Kitchener. In 2006, the 29th centre was added to the CAILC family. Every province except Prince Edward Island has at least one centre, with five in British Columbia, two in Saskatchewan, four in Quebec, and twelve in Ontario.

Table 7 lists all the Independent Living Resource Centres across Canada and the dates when they became members of the Canadian Association of Independent Living Centres. It is interesting to note that some groups began as non-profit organizations and evolved into centres while others were founded originally as Independent Living Resource Centres.

Table 7
Independent Living Resource Centres Founded Across Canada

1982	ILC of Waterloo Region, Kitchener, ON

1984	ILRC, Winnipeg, MB
	ILRC of Calgary, Calgary, AB
1985	Centre for Independent Living in Toronto (CILT) Inc., Toronto, ON
1987	ILRC Thunder Bay, Thunder Bay, ON
	CRVA Région du Bas-Saint-Laurent, Trois-Pistoles, QC
1988	ILC Kingston, Kingston, ON
	Ottawa ILRC, Ottawa, ON
1989	Nanaimo & Region ILRC Association, Nanaimo, BC
	Niagara Centre for IL, St. Catharines, ON
1990	Disability Resource Centre (DRC), Duncan, BC
	Victoria DRC, Victoria, BC
1991	North Saskatchewan ILC, Saskatoon, SK
	CRVA d'Abitibi–Témiscamingue, Val d'Or, QC
1992	South Saskatchewan ILC, Regina, SK
1993	Breaking Down Barriers: An ILRC, Collingwood, ON
	ILRC Halifax Regional Municipality, Halifax, NS
	Vernon, DRC, Vernon, BC
1994	DRC for Independent Living, Kapuskasing, ON
1995	ILC—London, London, ON
1997	ILRC, St. John's, NL
1998	RISE, Parry Sound, ON
1999	CRVA—PA inc., Shippagan, NB
2000	DRC, Richmond, BC
2001	CRVA du Montréal-Métropolitain/Montreal Metropolitan ILRC, Montreal, QC
2002	ILRC Corp., Sudbury, ON
2003	Miramichi ILRC, Miramichi, NB
2005	Regroupement Des Personnes Handicapées, Région du Haut-Richelieu, St. Jean-sur-Richelieu, QC
2006	Le Phénix, Alfred, ON

The Non-Profit Sector: In Need of Innovation

Since the 1960s, the non-profit sector in Canada has played a major role in the provision of supports and services to people with disabilities. The conventional approach to service provision in the non-profit sector has been driven by several concepts. First, funding goes from government to community agencies, which determine priorities and programs for service users. Second, most decisions in these agencies are made by professionals, not the user or consumer. Third, the focus is typically on rehabilitation or formal, paid support. Although consumer participation has increased within conventional service agencies in recent years, it is often more of a token participation, and the three underlying concepts described above remain the essence of how services have traditionally been provided.

In the 1980s and 1990s, there were growing criticisms of the non-profit sector and its approach to supporting vulnerable citizens. The criticisms came from many sectors. Many people with disabilities argued as consumers that service systems were stigmatizing, controlling, and patronizing. Many family groups also raised concerns related to the lack of individualized supports and the tendency of service systems to segregate children with disabilities from their peers. Several scholars were also critical of the narrow focus of service systems and their failure to support the building of relationships and sense of community. At the core of these criticisms was the crux of the problem: service systems contributed to a sense of powerlessness and lessened people's capacity to be full citizens.[1]

These criticisms showed that the non-profit sector was in need of more innovative approaches to supporting people with disabilities. This need for innovation is not limited to non-profit agencies serving people with disabilities. This was recently confirmed in a comprehensive *National Survey of Non-Profit and Voluntary Organizations*, completed on a sample of 161,000 non-profit organizations across Canada. The study identified several success factors for effective non-profits, including social innovation capacity, leadership, and entrepreneurship. This research found that successful non-profit organizations are open to change, willing to try new things, and are creative in their response to citizens.[2]

In many communities across Canada, Independent Living Resource Centres have been responsive to consumer demand and to the need for innovation.

Independent Living Resource Centres intentionally shift power to people with disabilities, both for governance decision making and to those who require support. In this way, centres are able to set themselves apart from many of the criticisms of traditional organizations. Although they experience similar issues that other non-profits face, such as human resources and funding, the philosophy and principles of the Independent Living movement have served as an additional grounding for centres in the new paradigm.

New paradigm thinking that emerged in the 1980s has deepened over the last two decades. Although the Independent Living principles are part of the new paradigm, other areas of disability have also been contributing to its development. Across all areas of disability, for example, human rights and social inclusion have become important goals. Similarly, self-determination and consumer control are increasingly seen as central to new paradigm thinking. Some have called this approach a *new story*, to contrast it with the more traditional services provided by most conventional agencies.[3]

Peggy Hutchison, professor at Brock University in St. Catharines, Ontario, has been involved in several studies on Independent Living. In recent studies, Hutchison and her colleagues found that Independent Living Resource Centres were indeed unique in the non-profit sector.[4] "The consumer-driven nature of the centres is key," says Hutchison. She identifies two other factors: "the cross-disability orientation and the grassroots approaches used by centres." Hutchison also points out that the IL philosophy has helped centres to stay innovative and to be entrepreneurial. Hutchison's studies confirm that ILRCs "give voice to people with disabilities." By exploring the development of Independent Living Resource Centres, we are able to learn about the struggle that they have undergone to maintain their uniqueness in the non-profit sector.

The Making of a Centre: Richmond, British Columbia

When Frances Clark began chairing the Richmond Committee on Disability in 1985, little did she know that this was the beginning of a long journey toward creating an Independent Living Resource Centre in Richmond, British Columbia. Like many Independent Living Resource Centres across Canada, the need for a community-based centre led by people with disabilities was identified as a need several years before it became a reality.

Frances Clark was the ideal person to chair a group that wanted to develop a centre. She had owned her own business and had been the civic affairs representative for the Richmond Chamber of Commerce for a number of years. In that role, she attended every city council meeting. Vince Miele, current chair at the Richmond Centre, says that Clark's leadership was critical. "The big bonus for our leadership," says Vince, "is that Frances was well known in the community and had lots of connections. Having those connections really made it easier for us as a grassroots group to go out and get support."

The leadership of the Richmond Committee on Disability reflected the mindset of Independent Living right from the beginning. Frances Clark recalls going to Victoria to a CAILC Conference in the mid-1990s, and hearing about Independent Living for the first time. "When we heard the discussions, we made it clear to CAILC that this was our vision, to set up a centre." Clark's colleagues with the Richmond Committee on Disability were in full agreement, and shortly afterward, they set about completing a community needs assessment in Richmond about issues related to disability and Independent Living.

Even before becoming a centre, the Richmond Committee showed perseverance in relationship building and fundraising. Vince Miele notes how important it was to have funding partners in order to build credibility. It took four years to get city council on side; however, this would prove to be a significant relationship in the future of the centre. The council eventually built the Richmond Centre into its city budget. Soon after that, the United Way became a funder. Frances Clark was also able to

Frances Clark (left) and other representatives at the opening of the new Disability Resources Centre in Richmond, 2008

convince the Vancouver Foundation of the merit of a centre and they also became a funder and supporter.

In reflecting on this period, Clark says, “The key is to approach people, have conversations, and build partnerships.” Clark stresses that “listening” is important, because “you are picking up information” and finding the places where others can support your efforts.

Frances Clark, Vince Miele, and their colleagues with the Richmond Committee on Disability were using a community development approach to build interest in starting a centre. This approach to change is typical of people who start innovations. The committee developed a clear message about the need for a resource centre for Independent Living. They sought out people and organizations with whom they shared common ground. They built momentum in ways that attracted people who originally were not involved.

Like much innovation, the path was never predictable and the leaders were wise enough never to try to control it too much. Instead, they took advantage of opportunities to build capacity and connections. Shortly after the centre opened in 2000, for example, they asked Richmond city council to approve them as the agency responsible for providing disabled parking cards to citizens with disabilities. This has allowed the centre to have access to a broader base of people with disabilities, and it means that more people are coming into the centre, who can then connect with other resources.

This kind of approach to reaching out has meant that the Richmond Centre now has funding support from several foundations, community organizations, and governments. These partnerships are contributing to a relevant organization that is having significant impacts for the citizens of Richmond.

The Richmond Centre is called the “Disability Resource Centre—in support of Independent Living.” Like most centres across Canada, it reflects its own city history and culture. The multi-cultural nature of Richmond is alive at the centre, with brochures available in seven languages, and staff and volunteers who speak several of those languages. Ella Huang, current executive director, describes the culture of the centre: “Everybody here has got a very positive attitude. I think the positive attitude rubs off on the consumers and they see how independent we all are. We also tackle projects in a positive way by reframing issues so they are manageable.”

Huang's positive energy reflects the spirit of a centre that is dedicated to Independent Living!

More Than Just Another Human Service: An Inside Look at an IL Centre

It does not take long for a visitor to an Independent Living Resource Centre (ILRC) anywhere in Canada to experience the IL principles in action. From one perspective, we discover that an ILRC *is a place* where consumers go for information, mutual support, and education. It is also a place that validates the experiences of people with disabilities. People are valued here for who they are! The centre is in an accessible location, where offices and a community room are designed to create a welcoming atmosphere. In a typical day, a variety of consumers, staff, and other community members are in and out of the centre for meetings, information sharing, and peer support. The coffee pot is always on!

From another perspective, we quickly discover that the centre *is people*, a broad-based network of consumers and others working together on significant community and disability issues. A diversity of people can be found on the staff leadership team. These folks all have in common a deep commitment to Independent Living. This network of people extends well beyond the walls of the centre and is reflected by the energy shown at community meetings, board meetings, and in partnerships with other community organizations. As one example, several centres are collaborating with literacy organizations to ensure that consumers have access to high-quality literacy training.

From a third perspective, the centre *is about programs and possibilities* specifically designed to meet the needs and aspirations of citizens with disabilities. All programs, whether they are an employment initiative, a peer support project, or a community development enterprise, are designed with the intention of enhancing consumer control and participation. Although there are programs at the centre, one senses more that there are possibilities for learning and participation. One researcher describes centres as "learning organizations."

The final perspective within an ILRC is not always easily recognizable. It is the *commitment to process*. This commitment is about the respect one feels in such a setting, and the honouring of the decisions people make about their own lives. A leader within a large centre describes the process as "facilitative as opposed to bureaucratic." One study found that consumers were treated positively at centres, and consumers attributed this to good communication, accessible information, and good process for dealing with issues and problems.[5] Good process at centres is also very much about valuing participation.

The story of Michelle Lenardon from Thunder Bay illustrates the multiple ways an Independent Living Centre assists individuals. Lenardon credits the Thunder Bay Centre with connecting her with the community. "The Independent Living Centre helped me get linked up with a contact person in order to sing in Sweet Adelines[6]," says Lenardon, "and through that experience in this choir, I gained a lot of singing experience and met some wonderful, helpful people." Lenardon subsequently had a chance to contribute to her community, by singing at variety shows, seniors' homes, and Harmony for Hunger to raise money for food banks. The Independent Living Centre was also very helpful to Michelle Lenardon when she moved out on her own. Finally, Lenardon says, "I received help with employment opportunities from people at the Independent Living Centre when I had jobs at Eddie Bauer clothing store and when I had a job as an assistant to the Project Facilitator with the Self Advocate's Council." Lenardon says that each time she went to the centre, staff were very encouraging and supportive, by listening closely and building on her strengths and gifts.

Independent Living Resource Centres: Core Functions

Since its inception, the Independent Living movement has identified core functions of an Independent Living Resource Centre. As we shall see, the functions, also known as core programs, create a framework for centres that enables them to move ahead with the IL principles. Table 8 outlines the core functions that were originally established for Independent Living Resource Centres. As we shall see, the core functions have changed slightly over the years, but the heart of the original four remain within all centres across Canada.

Table 8
Original Core Functions of Independent Living Resource Centres

Information and referral is a function that provides a wide range of information to consumers and to the wider community. It also serves to connect consumers with organizations and people who might be helpful. Educational workshops are often used to supplement existing information and as a way to enhance informed choice.

Peer support refers to the mutual support that people with disabilities provide to each other. Peer support can be a program, such as peer counselling or a peer support group. It also reflects a philosophy or principle, where peer support serves as an ongoing approach that centres use in any dealings with consumers.

Individual advocacy is an approach that centres use to support consumers to address and overcome barriers people face in their personal and community lives. Individual advocacy functions include supporting the person to advocate on their own behalf (self-advocacy) and advocacy *with* the person. In either case, consumer direction guides any advocacy.

Research and development is a function designed to respond to unmet needs of people with disabilities in their community. It includes doing research on key community issues, such as accessibility. It can also include demonstration of innovative approaches to service delivery, with the subsequent goal of spinning off this service to the community. It can also include the development of an IL service that the centre delivers on an ongoing basis.

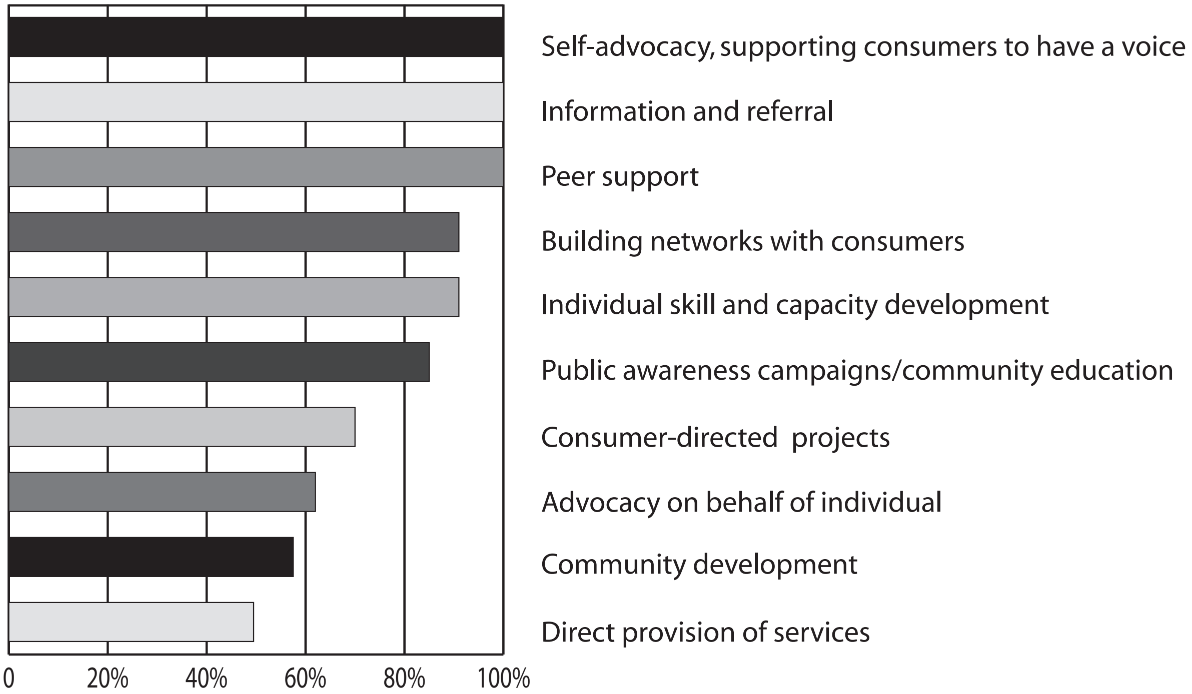
Information and referral has been vital to the development of new centres, as people with disabilities organize community resources and information in ways that are accessible and meaningful to consumers. When talking about information and networking, many people say, “Information is power.” Over time, this function has grown to include networking, not just referral.

Peer support, interestingly, is both a principle and a function. This is because its power lies in the connection and mutual learning that can take place between and among people with disabilities. Peer support has been shown to be most powerful when it is embedded in a consumer-driven organization, such as an Independent Living Centre.[7]

Individual advocacy is one of the ways that centres differ from typical human services. In standing with consumers in their struggle for dignity and citizenship, centres quietly support people to act on their dreams and goals. Over time, this function expanded to empowerment skills, which encompasses both advocacy and participation. In this way, empowerment skills development refers to the opportunities that centres create for people with disabilities to develop skills that are relevant to their dreams and goals.

Table 9 shows the processes and strategies used most often by Independent Living Resource Centres, as identified in a 2004 study by Peggy Hutchison and her colleagues. It is interesting to note how the core functions weave their way into most of the strategies. Education is also a key function and in many ways complements information functions.

Table 9
Independent Living Resource Centres:
Processes and Strategies Used Most Often



Adapted with permission from Peggy Hutchison, "Role of Consumer-Driven Organizations in the Non-Profit Sector," 2004.

Research and development creates opportunities for centres to explore how services and supports for people with disabilities can be developed and delivered through an Independent Living approach. It may involve research only, but can include demonstration projects and collaborative initiatives with other community organizations. Research and development enables centres to stay up-to-date on issues that impact people with disabilities in their community.

Building IL Functions and Programs One at a Time: The Trois-Pistoles Experience

In 1987, a few people in the Trois-Pistoles area of the province of Quebec fulfilled a dream. They founded the *Centre de vie autonome des Basques* (des Basques Independent Living Centre), the first such francophone centre in North America and the first in rural Canada to become a member of CAILC.

At the outset, the leaders involved spent their time sorting through an overwhelming volume of English-language documentation and meeting with other people with disabilities in large urban centres. They were committed to demonstrating the viability of this approach in a rural region, and rolled up their sleeves, got organized, and took things in hand. The process was marked by many concerns such as, "Is this what we want to do? Why is everything in English? Have we understood things correctly? Are we on the right path?" So many questions to be answered!

In 1989, the pioneers of this rural centre established their first program, "*l'information et l'orientation*" (information and guidance). The new centre was aware that disseminating information was one of the most common activities performed by Independent Living organizations, and it set about providing the region with several such services. This took the form of a resource centre, some directories, other reference tools, and a newsletter.

Although the information and guidance service was important, the leaders soon realized that mutual assistance might be a more appropriate way to develop an organization that wanted to be unique and different from other social services. So, in 1990, the centre took on a new role as a service provider. That year, seven students were hired, thanks to a federal summer employment program and support from the John Labatt Foundation. These young people went into people's homes to support them, help them with daily tasks, accompany them on outings, and give their family members some respite. People receiving the supports from these students were shocked to learn that they themselves were expected to get involved in organizing the activities for which they were requesting assistance! The Independent Living philosophy started to sink in. The message boiled down to, "Help yourself, then the CVA will help you!" People did, however, face a learning curve to shift their thinking about themselves and apply Independent Living principles to their daily lives.

Michelle Beaulieu arrived at the centre in 1991 with a lot of background knowledge. Beaulieu's humanistic approach, and her ambitions for the centre, helped her move ahead with some critical ideas. She examined the need for mutual assistance and consulted people to determine whether they wanted to get directly involved in organizing activities such as coffee hours, support groups, and peer support. Expectations were high with respect to developing mutual assistance activities between people with similar personal experiences.

Later that year, Health and Welfare Canada made it possible to add the program "*Soutien entre pairs*" (peer support). Finally, working with the members and giving them opportunities to take things in hand was becoming a reality! People could set goals, learn to try new things, experience the joy of success (along with some disappointments), and, above all, be proud of taking action on their own behalf. Workshops and coffee hours were now being held every week, and personal projects were springing up like mushrooms.

Leaders gathered together in Trois-Pistoles

The organization was able to begin offering something fundamental that lies at the heart of any Independent Living organization. Beaulieu noted that the means to share information, improve quality of life, and change things, were not only in one's physical and social environment but also inside oneself. People's attitudes were changing! Some people discovered skills that they never knew they possessed. They stopped focusing on their disabilities and defining themselves as "unable" (what they had often heard). They got used to seeing their own strengths, discovering their talents in various areas of daily life, and realizing their ability to develop these in others. Together, the leaders noted that this approach to improving the living conditions of people with disabilities was the right one. The goal was not revolution, but rather to give everyone the chance to set personal objectives, work toward achieving them, and learn things along the way, with advice from experienced peers. Forging ties and building individual and collective confidence—this is what the centre was striving to do, with the involvement of its members.

The centre's leaders felt it was necessary to start letting others benefit from the local experience, by expanding to the entire region. The board of directors also recommended a name change, which was adopted at the annual meeting. The organization would subsequently be known as the *Centre-ressources pour la vie autonome: Région Bas-Saint-Laurent inc.* (CRVA: Lower St. Lawrence Region Independent Living Resource Centre).

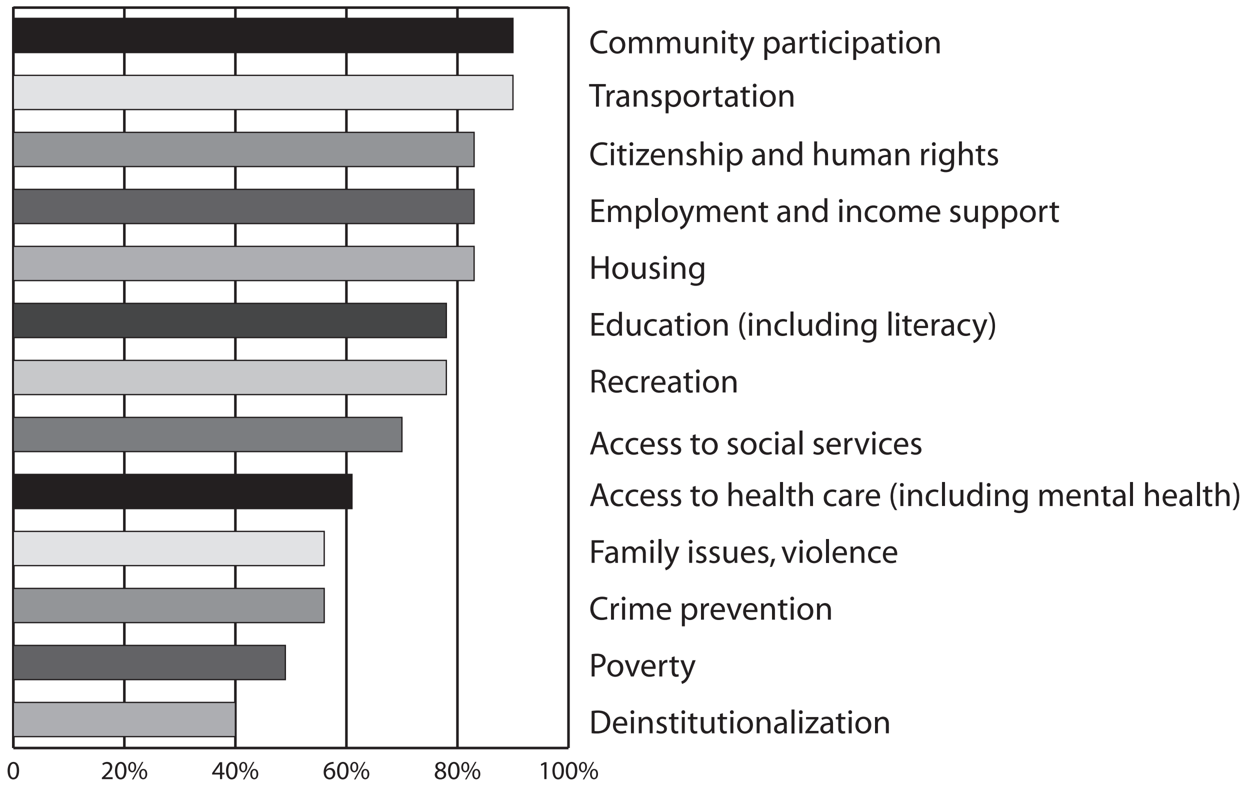
In 1993, the centre built momentum by launching its third program, "*Développement des aptitudes à la vie autonome*" (Developing Independent Living Skills). With four people hired on a permanent basis, the centre began to promote the principles of Independent Living to regional groups potentially open to its mission and values. Toward the end of that year, a regional process was developed as a study was conducted on the status of women with disabilities, which helped increase the centre's visibility in the region. Linda St-Maurice's leadership helped the CRVA's team take its place among the regional service providers, and become widely accepted as a significant player in the region.

By 1994, the CRVA succeeded in covering the Lower St. Lawrence with its "*activités de développement et de création de services*" (Service Development and Creation Activities), which was the fourth core Independent Living Resource Centre program to be implemented. Different projects sprung up, including *"Femmes handicapées et droit à l'autonomie*" (Women With Disabilities and Their Right to Independence), led by Linda St-Maurice; "*Garderies du futur*" (Daycares of the Future), led by Michèle Plourde; and "*Aide aux travailleurs accidentés*" (Assistance to Injured

Workers), led by Denis Lévesque. Through these regional projects, it became apparent that there was an urgent need to make staff in the region's organizations more knowledgeable about the rights and potential of people with disabilities. As a result, a satellite office was opened in Rivière-du-Loup.

Table 10 shows the projects and issues addressed by ILRCs. It illustrates that community is the focus of the centres and that the issues they address are critical to the lives of people with disabilities.

Table 10
Independent Living Resource Centres:
Projects and Issues Most Often Addressed



Adapted with permission from Peggy Hutchison, "Role of Consumer-Driven Organizations in the Non-Profit Sector," 2004.

Key Elements in Developing and Maintaining a Centre

Most Independent Living Resource Centres across Canada have similar experiences to Kitchener–Waterloo, Richmond, Trois-Pistoles, and Winnipeg. These experiences point to some key elements in the development and maintenance of a centre.

First, *centres develop in response to community needs*. This represents the true grassroots nature of the Independent Living movement as communities themselves identify their individualized needs and capacity to open a centre. All centres have used a variety of needs assessment approaches to determine the priorities of people with disabilities. This community research has typically identified needs, gaps, and barriers. As the Trois-Pistoles experience demonstrates, community research is not just a one-time affair, but must be ongoing to allow centres to change and adapt as they evolve. CAILC has developed a very useful *Citizen Engagement Tool* that can serve as a guide for community consultation during the development of a centre.[8]

Centres have learned that they must identify initial goals that are appropriate for their community without being so narrow that other possibilities cannot emerge through continued dialogue with people with disabilities. Kitchener–Waterloo's early commitment to housing almost consumed them, but over time they were able to balance this with other IL functions. Calgary, one of the earliest centres, focused on people with disabilities in institutions and had some significant impacts in that area. This focus, however, meant it took the Calgary Centre some time and effort to establish a balanced approach to its functions. Other centres have also struggled to find balance with core functions, but confirm that all functions continue to be valued and meaningful.

Second, *leadership from people with disabilities is critical to the development and maintenance of centres.* Although persons with disabilities have been the driving force behind the establishment of centres, as the Richmond story outlines, success is often measured by the organization's ability to build networks and partnerships throughout the community. With respect to the broader movement, we have seen how crucial leadership by people with disabilities was in the early days of the Independent Living movement. People like Henry Enns and Allan Simpson played significant roles in the development of the first two centres. Subsequently, leaders with disabilities emerged within each community where a new centre was being considered. This core group of citizens with disabilities provided the impetus for centre development and became the voice for Independent Living in that community.

Studies on the Independent Living Resource Centres have identified four ways that people with disabilities have provided leadership in the development of centres:

- Articulating a vision and commitment;
- Demonstrating the competence of people with disabilities;
- Ensuring that the consumer perspective is central to the IL philosophy;
- Building links between consumers and the IL movement.[9]

These four elements of leadership have been shown to play a key role in the development of what social scientists call "social capital."[10] Social capital includes the ability of people to work together for common purposes. Social capital thus builds upon leadership features such as trust, the sharing of values, and development of networks. Leaders with disabilities influence social capital within their centres by bringing their voice, values, and strengths as consumers. As well, they bring their networks and connections with the wider disability movement. Kathy Bloomfield's story in Table 11 reflects how this kind of leadership is both personal and political.

Leaders without disabilities have also been significant in the development of centres, usually in the role of providing tangible expertise. Some centres had connections with church leaders; others had connections with academics in universities, while still others drew in key leaders from social services or social planning. Leaders without disabilities have been warmly included in the IL movement, as long as their efforts support people with disabilities to be the leaders and directors of change.

Table 11

Leadership Is Personal and Political: Kathy Bloomfield's Story

Kathy Bloomfield's experience with disability and social change shows how leadership is both personal and political. As a former executive director of the Collingwood Centre, Breaking Down Barriers, Bloomfield says, "I kind of grew with the centre."

Kathy grew up in the community of Honeywood, population 100. The elementary school was not accessible, so her mother had to carry her up a flight of steps each day for her to attend, and busing to high school involved having a wheelchair at home and one at school to transfer to at the end of the ride. Still, says Kathy, "I think even in public school I always was kind of leading things," such as organizing drama groups.


Kathy Bloomfield

Kathy's personal situation and her leadership skills continued to influence her life choices. Attending the University of Waterloo in the early 1970s, Kathy got into wheelchair sports and accessibility issues on campus and in the community. She got married, went to work for the Board of Education, then the March of Dimes, and was part of a committee that convinced the city of Waterloo to build curb cuts on their sidewalks. She and her husband moved back to Honeywood in 1981, where they bought a farm and raised chickens and rabbits.

Kathy Bloomfield's strong sense of leadership served her well when, in 1985, she began working in Collingwood on an accessibility guidebook for the Georgian Triangle. "We tried to bring people together to start a group, to carry on the work we were doing," she says. The Georgian Accessibility Project (GAP) only lasted three years due to funding and interpersonal issues, but did manage to get a para-transit service started in Collingwood in 1989. "I came to realize that some of the work we were doing with skills development or individual advocacy was IL work," says Bloomfield. "We just didn't know what to call it."

GAP, which involved people with disabilities and representatives of service organizations such as the Lions Club, would form the beginnings of a board for a new organization, which would become an Independent Living Centre called Breaking Down Barriers. Kathy was hired as the first executive director, and a Trillium grant would allow the fledgling organization to develop a peer support program.

Being a new executive director presented Kathy with quite a learning curve. She had never before had to ask for money, or hire employees, and says she was probably more nervous than the candidates she was interviewing. However, she learned quickly and brought her own unique leadership style to the centre. She was at home both bringing politicians into the centre and reaching out to the community. During her tenure as executive director, she made a point of getting consumers involved in elections. She would invite party candidates individually to the centre so consumers would have the opportunity to speak about the issues important to them. "To me it seems like it's the best way we can educate politicians, to work alongside them and to discuss some of the issues directly with them," Kathy says.

Now a disability consultant, Kathy has blossomed into an entrepreneur. She has returned to the centre part-time to continue to make her contribution to Independent Living while forging a path to even greater independence. Kathy Bloomfield's story breaks myths of disability and shows how leadership is both personal and political.

Third, *sustainable centres have developed strong supports in their communities.* As we saw from Trois-Pistoles and Richmond, initially a small group of leaders with disabilities evolved their connections to access support from the wider community. Often, centres developed initial support from one established organization. In the case of Richmond, once they had support from the municipality of Richmond and later the United Way, other doors began to open more quickly. The Calgary Centre had strong connections at the University of Calgary and this helped them frame their early work on brokerage and support circles, and opened possibilities with the research community.

As we saw with Kitchener–Waterloo and Winnipeg, developing community support is not always easy. Even today, new centres find that there are turf issues among community organizations and not everyone is welcoming of a new, consumer-driven organization. Sandra Carpenter, a leader within the Toronto Centre, notes that new centres need to learn to deal with the tension that often accompanies consumer-driven initiatives. Centres have learned that it is not wise to seek public endorsement too soon. Working quietly with the disability community, building allies who understand the Independent Living principles, and creating strong, shared leadership can become the foundations for social capital and a centre that is sustainable.

Summary and Reflections

Independent Living Resource Centres can be considered a social innovation. From their inception, centres have played a unique role in the non-profit sector. Table 12 summarizes the elements that make centres stand out among a wide variety of disability organizations in most communities. Several of these elements will be explored in greater depth in subsequent chapters.

We have identified several elements that account for the success of Independent Living Resource Centres. Foundational to this success is the connection between local centres and the national Independent Living movement. The strong link between local centres and CAILC helps ground the philosophy of the IL movement. In a recent study, centres across Canada were shown to share values with the national organization.[11] This strong connection between local and national organizations is unique in the non-profit sector. It provides a common direction for centres across Canada and creates a strong network of people committed to innovation.

Table 12
Independent Living Resource Centres:
Elements That Enhance Their Innovative Nature

1. Consumer-driven and controlled—in governance, in policy, in programs, and in working with consumers;
2. Guided by values of the new paradigm of disability and community—self-determination, citizenship, and social inclusion;
3. Strong coherency and connections between local centres and the national Independent Living movement, represented by CAILC (now called Independent Living Canada);
4. Core functions/programs that address key, universal issues facing people with disabilities.

In conversations with people from a variety of Independent Living Resource Centres, we have been struck with the thoughtfulness of leaders and members. Innovation researchers have recently postulated that the capacity to think is critical to social innovation.[12] We know that how we think about things influences how we act, and can even be considered part of action. The strategic thinking of the early leaders in Richmond and Trois-Pistoles is noteworthy. They were always searching for better ways to connect with members, better ways to attract funders, and better ways to build capacity with others in their communities.

The unique elements of Independent Living Resource Centres do not mean that all centres have made it. Quite the contrary! Social innovation theory and research teaches us that innovation is a process of ever-changing dynamics. As we learned from Trois-Pistoles, functions change in response to consumers and the wider community, and are very much related to leadership capacity at the time. Because change is constant, what is innovative today can be the status quo tomorrow.

Centres have had to work very hard to maintain that sense of innovation and uniqueness. Some have managed to maintain an ongoing spirit of social innovation, others have had their ups and downs, while still others have struggled to flourish. As we shall see, this ebb and flow is very typical of organizations that are working against traditional paradigms. While unique in many ways, Independent Living Resource Centres continue to struggle for legitimacy, funding, and influence. At least, as CAILC Board Chair Paul-Claude Bérubé says, the maturing of the centres has made this struggle easier.

> *There are no perfect people. There are no perfect projects. We are not measured against perfections, only called to do what we can, to set out on an imagined destination, an imagined good.*
>
> — Frances Westley, Brenda Zimmerman, Michael Patton, *Getting to Maybe: How the World Is Changed*

Endnotes

1 Some of the most useful critiques include: I. Illich, *Disabling Professions* (London: M. Boyers, 1977); L. Noel, Intolerance: A General Survey (Montreal: McGill-Queens University Press, 1994); M. McCubbin, T. Spindel, and D. Cohen, "Paternalism: The Underlying Ideology of Disempowering Practice," *The Rights Tenet: Quarterly Newspaper of the National Association for Rights Protection and Advocacy* (Summer 2002): 4, 20–21; John McKnight, *The Careless Society: Community and Its Counterfeits* (New York: Basic Books, 1995).

2 "Imagine Canada," *National Survey of Non-Profit and Voluntary Organizations*, (Ottawa: Canadian Policy Research Networks, March 2006).

3. John Lord and Peggy Hutchison, *Pathways to Inclusion: Building a New Story with People and Communities* (Toronto: Captus Press, 2007).

4 P. Hutchison, A. Pedlar, J. Lord, P. Dunn, M. McGeown, A. Taylor, and C. Vandetelli, "Impact of Independent Living Resource Centres in Canada," *Canadian Journal of Rehabilitation*, 10, no. 2 (1997): 99–112.

5 Ibid, page 105.

6 Sweet Adelines is an international group of women singers that promotes four-part harmony singing in the "barbershop" style.

7 For a more complete analysis of peer support, see Chapter 7; also see, John Lord and Peggy Hutchison, *Pathways to Inclusion: Building a New Story with People and Communities* (Toronto: Captus Press, 2007).

8 CAILC, *Citizenship Engagement Tool* (Ottawa: Canadian Association of Independent Living Centres, 2004).

9 See two studies on ILCs by John Lord and his colleagues. John Lord and Lynn Osborne-Way, *Toward Independence and Community: A Qualitative Study of Independent Living Centres in Canada* (Ottawa: Disabled Persons Participation Program, Government of Canada, 1987); and John Lord, Mary McGeown, Andrew Taylor, and Sherri Young, *More Than Just Another Human Service: Independent Living Centres in Ontario* (Ottawa: Canadian Association of Independent Living Centres, 1992).

10 Robert Putman, *Bowling Alone: The Collapse and Revival of American Community* (New York: Simon & Schuster, 2001); Peggy Hutchison, Susan Ari, Alison Pedlar, John Lord, Colleen Whyte, "Leadership in the Canadian Consumer Disability Movement: Hopes and Challenges," *International Journal of Disability, Community, and Rehabilitation,* 6, no. 1 (2006).

11 Peggy Hutchison, Susan Ari, Alison Pedar, and John Lord, "Consumer-Driven Organizations in the Non-Profit Sector," *Disability and Society*, 22, no. 7 (2007): 701–716.

12 Frances Westley, Brenda Zimmerman, and Michael Quinn Patton, *Getting to Maybe: How the World Is Changed* (Toronto: Random House, 2006).

Chapter 4

Solidifying the Movement: The Birth and Growth of the National Association

By 1985, there were four Independent Living Resource Centres in Canada—Kitchener, Winnipeg, Calgary, and Toronto. As the number of centres grew, leaders began to talk about the possibility of forming a national association. The birth of the Canadian Association of Independent Living Centres (CAILC), now called Independent Living Canada, is considered a significant milestone in the history of the Independent Living movement in Canada.

Several factors made the mid-1980s a good time to try to solidify the Independent Living movement by forming a national organization. During this time, the federal government was showing a lot of interest in Independent Living Resource Centres but did not want to negotiate funding with each one separately. This opportunity to partner with the federal government was putting some strain on individual movement leaders, since no one person or organization had the authority to make decisions collectively on behalf of the centres in collaboration with the government.

The federal government had funded a study of the first three centres in Canada, signalling a need to collaborate on issues of Independent Living. John

Lord, lead researcher on this study, notes that the research itself created an opportunity for the leaders to work together. "The study had a steering committee," says Lord, adding that, "This brought the leaders from the first three centres together with the federal government and researchers for the first time. These meetings were extremely valuable for movement leaders, since common ground was quite easily achieved by all the stakeholders."

One other factor was pushing movement leaders to create a national organization. Several new communities were beginning to show an interest in developing Independent Living Resource Centres, and they wanted support and resources. Although leaders of all the centres were in contact with each other, they began to realize they needed some kind of body to be their national voice. It was also becoming clear to experienced leaders that an administrative vehicle was needed so that new centres would receive the support they required. Some leaders also noted that a national body would address quality assurance issues related to both new and established centres.

Initial Dialogue Among Four Centres

Representatives of the four initial centres, along with stakeholders from a variety of communities that were interested in developing centres, gathered in Kitchener in January 1985 to consider how they could work together. Leaders at that meeting recognized that there were strong common interests among the centres. "Everyone felt deeply connected and committed to the Independent Living philosophy," says one leader who attended. This strong value base made it relatively easy for people at this meeting to find common ground on what would shape their future. Delegates to this Kitchener meeting developed consensus on three key issues.

First, there was agreement that the federal government was beginning to recognize the validity of Independent Living. Walter McLean, Member of Parliament for Waterloo and then-Secretary of State for the federal government, attended part of this initial meeting, and confirmed the government's recognition. Roy Steckley, representing the Kitchener Centre at that meeting, recalls how important Walter McLean was to the evolution of the movement. "Walter was able to convince the federal government of the importance of our movement and that was huge," says Steckley. As former CAILC staff person Fraser Valentine says, “Formal government recognition was an important first step in the development of what has become a positive partnership between the federal government and the Independent Living Centres.”[1]

Second, this initial meeting developed a clear definition of an Independent Living Resource Centre. There was broad consensus that centres “were to represent a focal point for persons with disabilities to define, develop, and implement resources that are needed to assist them to be independent and fully participate in Canadian community life.”[2] The definition reads as follows:

> **Independent Living Resource Centres promote and enable the progressive process of people with disabilities taking responsibilities for the development and management of personal and community resources.**

Clarifying the definition at the time was important. Henry Enns made it clear to the group that his contacts within the federal government had told him that the concept of Independent Living was still rather vague. The creation of this definition gave structure and direction for the national association.

It is worth noting that the creation of a Canadian definition of Independent Living was an important task for the leaders, as they needed to shape this movement so that it was applicable to Canadian realities. Paul-Claude Bérubé, current CAILC chair who was involved in the founding meetings, notes that, “We drew a lot of inspiration from the American experience, which went back to the early 1970s…except, of course, we made adaptations to ensure the Canadian model had its own identity.” Although the Canadian movement can trace its roots to the Independent Living movement in the United States, the movements are in fact quite distinct, and these differences further illustrate the importance of a national coordinating body for the Independent Living movement in Canada.

For example, in the US, the Independent Living model was designed to promote collective advocacy and place a greater emphasis on an alternate method for the delivery of disability-related services.[3] Following the initial definition, the Canadian movement evolved with an emphasis on individual skills development and initiatives led by people with disabilities. In Canada, Independent Living has been about empowering the individual to self-identify positive change. Centres are designed to facilitate greater independence through the active and meaningful involvement of persons with disabilities in all aspects of their lives. As such, the

Independent Living movement in Canada has evolved in a way that informs and complements the supports and services offered through the government and community agencies, rather than offering a parallel or competing system of service delivery.

Finally, this historic meeting included a great deal of dialogue about the need for a coordinating body that could represent the Independent Living movement at the national level. These discussions led to the development of a steering committee, whose role was to develop the rationale and role of a national association. This steering committee met over the next year and developed a constitution and bylaws. One of the most challenging issues was the size and composition of the board of directors. The steering committee settled on 15 members, including representatives from each province and members at large. Henry Enns was able to secure funding from the Secretary of State to hold an inaugural meeting and conference in May of 1986.

The National Association Is Born

The founding meeting of the Canadian Association of Independent Living Resource Centres (CAILC) took place in Ottawa on May 3, 1986. The five founding centres of CAILC were the Independent Living Centre of Waterloo Region, the Independent Living Resource Centre of Winnipeg, the Calgary Association for Independent Living, the Handicapped Action Group of Thunder Bay, and Centre de vie Autonome of Quebec City. Seven other communities had representatives at that inaugural meeting. They all indicated a desire to be considered for future membership, including Halifax, Vernon, Victoria, and Newfoundland and Labrador. Involvement from these diverse groups demonstrated that the growth of the movement had truly become a national enterprise. In turn, it was becoming clear that the education of and input from various sources (both member centres and non-members) would be vital to the growth of the movement and to the national association.

The mood in Ottawa on that spring day was quite celebratory. April D'Aubin, a member of the founding board, says that people were very excited that they had created a national organization. "There was a strong sense of common identity," explains D'Aubin, "because people who worked in Independent Living viewed themselves as doing something very different than what was traditionally done in rehabilitation." Paul-Claude Bérubé, also a member of the founding board, felt that representatives had common interests, but that it was much less obvious about a common identity. He points out that, "Other than our involvement with COPOH (Coalition of Provincial Organizations of the Handicapped), we had no shared identity related to the Independent Living movement. In that respect, everything had to be built from the ground up."

April D'Aubin notes that in 1986, "There was quite a big divide between traditional service providers and IL centre people. And centres wanted there to be a big difference between the two!"


Paul-Claude Bérubé (centre) with Rick Goodfellow, left, and Vince Miele

Paul-Claude Bérubé had similar feelings. He remembers at the outset that, "The concept of Independent Living was not very well received in Canada…especially by workers in various social services and health care systems. They saw the movement as a rejection of everything that was being done at the time. They hated hearing people talk about consumer control…. We were not perceived as people who wanted to take charge of their own lives, but as usurpers who were disrupting a very well-established system." Both D'Aubin and Bérubé believe that CAILC gave the Independent Living movement a chance to demonstrate and educate about the capacities of people with disabilities.

The stated purpose of the new national association was threefold:

- To promote the Independent Living movement within Canada, including advancing the Canadian definition of an IL centre and developing funding support for the centres;
- To bring the centres that support the movement under a national umbrella entity for consistency and focus; and
- To build and provide tools to help the development of Independent Living Resource Centres across Canada.

The founding board of CAILC included one representative from each of the founding centres, four provincial representatives from provinces that had centres, and four members-at-large. Muriel Keeling from Calgary became the first chair and Paul-Claude Bérubé from Quebec the vice-chair. Bérubé recalls the challenge of starting a national organization. "In light of the diversity of our cultural identities, but also the level of development of the concept of Independent Living in Canada, founding a national association was a substantial challenge, but one that the people involved rose to skilfully." In reflecting back on more than twenty years, Bérubé explains, "I have to say that we were not wrong at the start, and that the outcomes we've seen are tremendously indicative of the vitality of this movement in Canada." Although there were challenges, the CAILC Board of Directors had fun together right from the beginning. Bérubé says, "I remember having a lot of fun at the time working with the representatives from Newfoundland, whom I didn't know at all, and who were extremely kind."

By collaborating to develop a national association, the founding members created a vehicle for better decision making about the future. The national agenda now had a place for reflection and action. Perhaps not realizing it at the time, the national association also increased the innovation capacity of the young movement. Some social movements are stuck on ideology and never fulfill their vision. Strategies for change are required if social movements are to move from ideology to broad-based action. The Independent Living Resource Centres had already become the local vehicle for implementing the vision of Independent Living. Now, the Canadian Association of Independent Living Centres (CAILC) was becoming the national vehicle for this vision.

The founders of CAILC understood the synergy and relationship between local and national work and built that into the principles and bylaws of CAILC. Representation from a variety of regions on the CAILC board also helped keep the Independent Living movement energetic and grounded in the needs of people with disabilities. By focusing on a common vision, these diverse regions pull together for the common good.

In 1985, the idea of Independent Living Resource Centres being run by and for citizens with disabilities was still in its infancy in Canada. Yet, many people were being drawn to the idea, and small interest groups were springing up across the country. The new national association created a powerful and supportive link for these groups. CAILC was to become an important vehicle for spreading the innovation of Independent Living across Canada.

From Incorporation to Policy Influence

Paul-Claude Bérubé stresses that once the national association was incorporated, the Independent Living movement really gathered steam on its own. Bérubé notes, “I was still surprised to see that CAILC was able to find its own identity so quickly.” Once incorporated, the board of directors decided to move the national office from Winnipeg to Ottawa, which contributed to the further development of the national organization’s own identity. Mike Murphy from the Kingston Centre says, “This move to Ottawa was important in terms of political objectives and funding relationships.” CAILC wanted to be close to the federal scene and the government’s decision-making process.

Once in Ottawa, CAILC hired its first national director, Ross Robinson, and four other staff, including an organizational development officer, a financial resource consultant, a bilingual administrative support person, and a researcher. CAILC was now in a position to negotiate with the federal government about the federal government’s role in supporting Independent Living. As well, the national association wanted to influence and support the growth of the Independent Living movement that was soon to follow.

Within two years of incorporation, CAILC had added three more centres as members—Ottawa–Carleton, Trois-Pistoles, and Kingston—and local communities in every province were showing interest in the movement. As the national association matured, it began to focus on two major areas: the development of national standards for centres, and relationship building and education with the federal government. This emphasis on both internal and external policy quickly gave CAILC credibility with other national organizations that were part of the disability movement. To connect with other parts of the disability movement, the national association went to other key national groups to seek endorsement for CAILC’s purpose and the definition of Independent Living. Such endorsements helped the movement expand its base of support.

The idea of national standards for Independent Living Resource Centres was precipitated by the range of requests being received by the new national organization. While the definition of IL was now clear, there was concern among national board members that the rapid growth of the movement could develop a momentum of its own. While innovators understand that they cannot control the way new ideas evolve, the board wanted to begin the process of identifying what IL was and what it was not!

The national board established a membership review committee that was charged with the responsibility of developing national standards for Independent Living Resource Centres. The idea was to develop some kind of accreditation that would enable centres as they evolved to be recognized at different stages of development. These ideas took hold very slowly, but as we shall see, today this process of standard setting enables centres and the public to know what principles they can expect from an Independent Living Resource Centre.

The first CAILC board understood that it would have to rely heavily on the federal government for funding if they were to be successful in developing centres all across Canada. Fortunately for the national organization, the federal government had been quite responsive to the disability movement since the late 1970s. As we have seen, the 1981 *Obstacles Report* further enhanced the visibility of disability issues on the federal scene.

In 1983, the federal government started the Office of the Minister of State on the Status of Disabled Persons. This was a significant initiative, because this office created a federal focal point for disability issues. It also shifted disability away from National Health and Welfare to the Secretary of State. As Aldred Neufeldt has written, this change meant that "disability would no longer be treated as solely a health or welfare issue, but as a human rights/citizenship issue."[4] In 1985, a Disabled Persons Secretariat was created within the Secretary of State, and in 1986, the secretariat initiated the Disabled Persons Participation Program (DPPP). With an initial annual budget of $3.2 million, DPPP was designed to support consumer groups who were addressing issues of social and economic inclusion.

The timing of these federal government initiatives could not have been better for CAILC, the newest and probably the most innovative of the national disability organizations. In 1986 and 1987, CAILC leaders did a number of presentations to the federal government to solidify people's understanding of

Independent Living. These included a presentation to the Canadian Assistance Plan (CAP) and to the Vocational Rehabilitation for Disabled Persons Program (VRDP) National Review Task Force. Independent Living was becoming known as a key concept in enhancing disability rights.

In January 1988, Henry Enns and Allan Simpson made a presentation to the Parliamentary Sub-Committee on the Disabled and the Handicapped. Their presentation stressed that the federal government should recognize the value of Independent Living. Furthermore, they presented a brief that outlined the principles and core programs and showed how core funding for centres across Canada would be cost effective and in the best interests of the federal government. In many ways, this report was masterfully written, with all the right language and arguments needed to persuade civil servants to recommend funding.

Typically, reports alone seldom produce the kind of change for which advocates hope. Fortunately for CAILC, other conditions helped their case with the federal government. Civil servants who were asked to work on the Independent Living file had already done a detailed analysis of the costs and possibilities of Independent Living. The CAILC proposal provided a catalyst for the civil servants to have further meetings with Independent Living leaders and to recommend to politicians that they fund Independent Living Resource Centres across Canada. Sue Potter, a former civil servant with the Disabled Persons Participation Program, says that Independent Living Resource Centres were seen as a "good fit" with the goals of the federal program, which were designed to enhance the rights and participation of citizens with disabilities.

The minister at the time was Jake Epp, a member of parliament from Winnipeg. Allan Simpson, national board member, had met Epp from time to time, but now made a concerted effort to reconnect with him. On a snowy night during the winter of 1988, Simpson went to the Winnipeg airport to meet Minister Epp as he returned from Ottawa. Simpson was able to have a frank and detailed discussion with the minister about the CAILC proposal and the benefit of the federal government playing a major role supporting the Independent Living movement. Jake Epp's Mennonite roots, and the Mennonite Central Committee's early support for Independent Living, probably helped make him responsive to Simpson's social justice arguments.

IL leaders in action, Allan Simpson and Lucie Lemieux-Brassard

Allan Simpson understood that for innovation to be successful, leaders must figure out how to connect with "powerful strangers." Research on innovation identifies three steps in how innovators connect with and influence people in power.[5] The first step is the development of connections, and Allan Simpson was a master of the art of connecting. The second step typically includes analysis and confrontation with power in others and in ourselves. Simpson was always comfortable in his own skin and understood that his power came from his ability to communicate from his own experience and ideas. He always believed that even those with assigned power were equal to the rest of us. In discussing power, Simpson always effectively linked it to the mission of Independent Living and its value to marginalized Canadians. The third step is learning how to collaborate with those in power. Simpson knew how to talk about social change with politicians and civil servants. He could argue persuasively that Independent Living was a "perfect fit" with the mandate of the federal government's Disabled Persons Participation Program. Allan Simpson was the ultimate relationship builder, and like many innovators, he knew when to advocate and when to collaborate. Simpson's ability to connect with powerful strangers is one reason that CAILC was successful with the federal government.

Founding CAILC board members April D'Aubin and Paul-Claude Bérubé both remember Simpson as the engineer of CAILC's work with the federal government. D'Aubin recalls how impressed she was with Simpson's skills as managing director of the Winnipeg Centre and how this knowledge served him well in his national work. Bérubé says that, "Allan was very knowledgeable about IL, but he was also respectful toward those around him, I would even say engaging. He had a gift for finding solutions that could reconcile two apparently opposing positions. For Allan, there were never problems…only solutions."

"Special Initiative" Agreement Signed: CAILC Forms Partnership With Federal Government

During the first national conference of the Canadian Association of Independent Living Centres (CAILC) in November 1988, the federal government made the announcement that CAILC had hoped would come. Jake Epp, Minister of Health and Welfare, made a statement that the federal government was forming a partnership with the Canadian Association of Independent Living Centres. Table 13 outlines part of the announcement.

Table 13
Federal Conservative Government Announces Partnership With the Independent Living Movement

November 10, 1988

The Honourable Jake Epp announced today the creation of a partnership between National Health and Welfare, the Secretary of State, and the Canadian Association of Independent Living Centres. Mr. Epp confirmed that this Special Initiative funding support would be used to advance a network of Independent Living Resource Centres in major Canadian cities and regions. With this announcement, the federal government has made a commitment to five years of funding for CAILC for the advancement of core programs and principles with Independent Living Resource Centres across Canada.

Henry Enns, Jake Epp, and Allan Simpson at the signing of the special initiative

This Special Initiative reflected the federal government's interest in disability issues in the 1980s and was inspired by recommendations of the *Obstacles Report*. During the previous year, the federal government had committed $1 million to deinstitutionalization projects. Roy Steckley, founding board member of CAILC, had accompanied Allan Simpson to meetings with Minister Epp. Steckley felt that the national association's ideas outlined a strong community alternative to institutions and that the federal government appreciated this option. At the same time, Minister Epp was holding a series of meetings with his provincial counterparts about alternative service delivery approaches. For the federal government, this announcement to contribute to the development and expansion of the Independent Living movement contributed to both those other initiatives.

The overall objectives of the Special Initiative were to:

- Demonstrate the Independent Living model;
- Assist persons with disabilities to integrate and participate fully in Canadian society;
- Establish a network of 23 ILRCs across Canada; and
- Secure provincial funding through the Canada Assistance Plan.

According to federal officials, the Special Initiative agreement was initially designed to kick-start the idea of Independent Living with the provinces and territories. With the development of centres, it was assumed that this would create a model for the provinces and would lead to provincial cost sharing for centres. The theory was that federally the Secretary of State would fund centre development, while Health and Welfare would fund core programs. Ongoing operations would be funded by the Canada Assistance Plan with cost sharing by the provinces.

As we have seen, the Special Initiative had four objectives, including the securing of provincial funding through the Canada Assistance Plan. As it turned out, only one province, Manitoba, entered into a cost-sharing agreement with its Independent Living Resource Centre in Winnipeg. The Canadian reality is that social services are a provincial responsibility and this agreement was thus fraught with jurisdictional problems. However, leaders from the national association at the time felt that the other three partnership objectives were fully achieved.

National Association Provides Leadership for the Movement

For the first five years, the Canadian Association of Independent Living Centres served primarily as an administrative arm of local centres. Leaders report that this was *a period of stability and learning*. New centres started in Kingston, Ottawa, Nanaimo, Niagara, Duncan, BC, Victoria, North Saskatchewan, and South Saskatchewan. Each centre obtained funding from the federal government. CAILC provided support in terms of training and background resources. At a conference in Winnipeg in 1992, leaders of the movement shared their ideas and reflections about the key Independent Living developments across Canada. The conference proceedings were published in 1993 as *Independent Living: An Agenda for the '90s*. This document became an important touchstone for what the movement had learned up to that point in its history.

When Traci Walters became national director in 1993, the national association was ready for a change. Walters came from the grassroots of the IL movement and did not have to prove herself to her colleagues in the movement. She had been executive director of the Niagara Centre for Independent Living and brought to Ottawa her extensive leadership experience and deep awareness of local issues facing centres. As one member said, "Traci lived and breathed Independent Living and she was passionate about the movement." The fact that Walters herself had a disability gave her a lot of credibility, and also meant that she personally understood Independent Living issues and was a good role model for others with disabilities.


Traci Walters, national director since 1993

When Traci Walters started as national director, the national association was moving beyond administration to look at projects that could have an impact on consumers and communities of local Independent Living Resource Centres. One such project, the National Family Violence Initiative, was getting underway. This initiative was designed to address family violence issues in collaboration with other key stakeholders. This project gave Walters a chance to see how a decentralized model would work with CAILC. This was the first time that the national organization involved three different centres in the development and implementation of a national project. Under Walters' leadership, CAILC and the centres began to work more collaboratively on a range of projects.

During the 1990s, there was rapid expansion across Canada, and CAILC had to balance centre support with national leadership. Between 1993 and 2000, eight new centres joined the CAILC family—Halifax, Vernon, BC, Kapuskasing, London, St. John's, Parry Sound, ON, Shippagan, NB, and Richmond, BC. As CAILC provided support to centres, they also had to deal with challenging national issues. In 1994, the federal government began to cut spending significantly as a way to reduce the national deficit, and CAILC had to advocate strenuously to maintain its federal funding.

By the mid-1990s, it was clear that CAILC and the centres had built momentum across the country. Traci Walters understood the importance of partnering with a range of groups to broaden both the message and the impact of Independent Living. Walters was also establishing CAILC's presence with other national disability organizations. CAILC and the Council of Canadians with Disabilities (CCD) began to partner on key national policy issues. Walters' forthright style brought the IL message to many policy tables and had an impact on how people viewed Independent Living.

Fraser Valentine, federal government civil servant and former CAILC staff person, says, "There is no question that the Independent Living movement was having huge success...I think its biggest success, in terms of attitudinal change, was in fact proving the IL model." There is little doubt that this growth in the movement would not have happened without federal government support. Yet, even when the government reduced its funding in the mid-1990s, the movement continued to grow. When CAILC published the independent research study *The Impact of Independent Living Resource Centres in Canada*, the positive results were no surprise to leaders in the movement. They had now seen the Independent Living approach in use for more than a decade and knew it was having an impact on individuals and communities. Walters recognized how important it was to have independent research completed on Independent Living, and she stressed that it deepened the movement's credibility.

Summary and Reflections

Some public interest researchers suggest that social change groups need to deal with two key issues: common interests and group identity. As the five centres began to consider the nature and composition of a national organization in 1985, they worked easily from a set of common interests. Everyone at the initial meetings wanted to both solidify the movement and create opportunities for expansion in the number of centres across Canada. Building a national organization to represent their interests was seen as the best way to do this.

Very quickly, the CAILC leaders also built a strong sense of group identity. Unlike other disability movements, people became close not because of a particular shared disability experience, but because of a shared vision of Independent Living. Sandra Carpenter from the Centre for Independent Living Toronto says, "The differences among individuals can only make the movement stronger, as centres and consumer groups can divide and share tasks and support one another."

Once the Canadian Association of Independent Living Centres was incorporated and moved to Ottawa in 1986, the Independent Living movement became a truly national enterprise. In 1988, when CAILC signed a Special Initiative agreement with the federal government for five years of funding, the status of the movement had grown considerably. Communities in all parts of the country were showing interest in Independent Living. At the same time, the federal government was sending a strong signal that Independent Living was one important way to build the future with citizens with disabilities. Table 14 summarizes some of the key elements in the development and expansion of CAILC and the national movement.

In comparison with other social movements, it is quite interesting that CAILC and the Independent Living movement were able to work so collaboratively with the federal government. Some social movements have found it a conflict to receive money from the federal government and continue to be independent. CAILC has managed to create a balanced approach that includes heavy reliance on government funding along with a strong voice for Independent Living. How has CAILC managed to do this?

First, it must be recognized that the Canadian disability movement has historically seen government as a key player for people with disabilities seeking to achieve rights and community supports. While some social movements have been anti-state, CAILC and most other national disability groups emphasize the important role of government in contributing to equality. As Fraser Valentine has written, "It is difficult to imagine how a pan-Canadian movement of people with disabilities could operate in Canada’s vast space, except with some government support. It is equally difficult to identify any recourse for disability movements other than the state (at whatever level), given the regulatory and support needs of persons with disabilities.”[6]

Table 14
Canadian Association of Independent Living Centres: Key Elements in Development and Expansion

Several factors played a role in the development and expansion of CAILC from its beginnings in 1986 to the mid-1990s. These elements together solidified and strengthened the national Independent Living movement in Canada.

1. The original five Independent Living Resource Centres built a strong group identity and found they had a common commitment—to create a national organization that would serve as their national voice.
2. The founders of CAILC understood the synergy and relationship between local and national work and built that into the principles and bylaws of CAILC. Centres were represented on the CAILC board and members-at-large represented the wider Independent Living movement.
3. Once incorporated, CAILC moved its national office to Ottawa to be able to influence politicians and the federal government more effectively. This also helped CAILC to be seen as separate from COPOH (now the Council of Canadians with Disabilities) who had played such an important role in the founding of the Independent Living movement in Canada.
4. CAILC leaders, especially Allan Simpson and Henry Enns, developed a strategic approach with the federal government. Strategies included building personal relationships with politicians and presenting detailed briefs on Independent Living to civil servants.
5. The federal government was quite responsive to disability issues in the 1980s and the Secretary of State Disabled Persons Participation Program (DPPP) created an opportunity for CAILC to receive ongoing national funding. The federal Conservative government signed a Special Initiative with CAILC, which included five years of funding to expand centres across Canada.

6. Traci Walters became national director in the early 1990s. Her leadership was instrumental in helping CAILC build on the momentum for Independent Living that was evident across the country. She also expanded the presence and voice of IL in the wider disability movement.

Second, CAILC was quite skilful at managing its partnership with the federal government. Although the Special Initiative agreement signed between CAILC and the federal government in 1988 gave CAILC five years of funding, the agreement had some guidelines that turned out to be troublesome. Despite this dilemma, CAILC was able to show the federal government that the other objectives of the Special Initiative, including the rapid expansion of centres, were being met. CAILC was thus able to maintain a strong presence and accountability with the federal government. In addition, two years after the Special Initiative was signed, CAILC worked with civil servants in the federal government to outline the roles and responsibilities of the partners in the agreement. Research shows that the most effective partnerships are those where there is a clear purpose as well as well-defined roles and responsibilities.[7] CAILC intuitively understood this, which helped their ongoing relationship with the federal government.

In many ways, the partnership between the national association and the federal government has been a benefit to both parties. CAILC benefits immensely from the resources they are able to earmark for centres across the country. By assisting the Independent Living movement to establish community-based infrastructure, the federal government was fostering independence of people with disabilities. One federal official indicates that federal government support for Independent Living was both a symbol and a strategy. Symbolically, it sent a strong message to Canadians that the federal government was supporting the independence and citizenship of persons with disabilities. Strategically, it meant that people with disabilities would ultimately be less dependent on the welfare system.

Although CAILC and the federal government have managed their partnership in ways that benefit both parties, the troubles with that Special Initiative in the 1980s remain unresolved today. The role of the provincial governments in the Independent Living movement is still very limited and jurisdictional issues remain unresolved. As we shall explore in subsequent chapters, the future of the national association requires a new framework and approach that broadens the stakeholders in the quest to make Independent Living more widely available for Canadians. Fortunately, by the turn of the century, CAILC came to the same realization and began to embark on a new direction.

> *The biggest job in getting any movement off the ground is to keep together the people who form it. The task requires more than a common aim: it demands a philosophy that wins and holds the people's allegiance; and it depends upon open channels of communication between the people and its leaders.*
>
> —Martin Luther King, *On Leadership*, 1959

Endnotes

1 Fraser Valentine, *The Canadian Indpendent Living Movement: An Historical Overview* (Ottawa: Canadian Association of Independent Living Centres, 1994), 21–22.

2 Ibid, 22.

3 Fraser Valentine, *Locating Disability: People with Disabilities, Their Movements and the Canadian State* (Master's thesis, Carleton University, 1996).

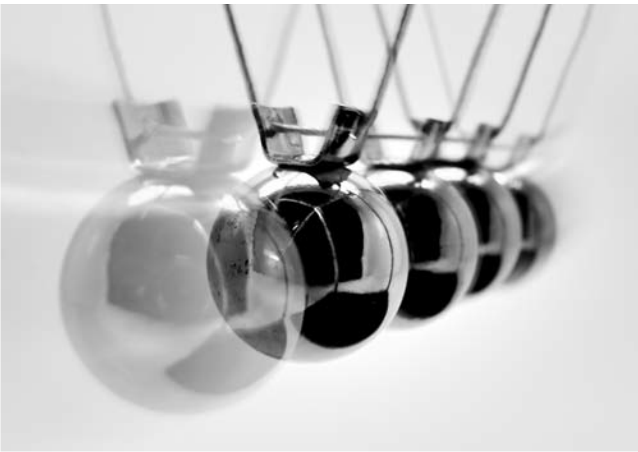
4 Aldred Neufeldt, "Disability in Canada: An Historical Perspective," in *In Pursuit of Equal Participation: Canada and Disability at Home and Abroad*, eds. Henry Enns and Aldred Neufeldt (Toronto: Captus Press, 2003).

5 Frances Westley, Brenda Zimmerman, and Michael Quinn Patton, *Getting to Maybe: How the World Is Changed* (Toronto: Random House Canada, 2006). For further insight into the issues that faced the early leaders, see Aldred Neufeld, Ross Robinson, and Nathalie O'Neil, eds., *A Vision for Independent Living in the '90s* (Ottawa: Canadian Association of Independent Living Centres, 1990).

6 Fraser Valentine does a detailed analysis of the disability movement in Canada with special reference to the federal state: *Locating Disability: People with Disabilities, Their Movements and the Canadian State* (Masters thesis, Carleton University, 1996): 115–116.

7 John Lord and Kathryn Church, "Beyond 'Partnership Shock': Getting to 'Yes,' Living with 'No,' *Canadian Journal of Rehabilitation* 12, no. 2 (1988): 113–121.

PART II



Impact and Influence of Independent Living

Part II explores some of the ways that Independent Living is having an impact and influence on individuals, communities, research, and policy.

Chapter 5

Impact of Independent Living on Individuals: Empowerment, Competence, and Leadership

Each year, between 200,000 and 250,000 Canadians utilize the supports and services of Independent Living Resource Centres. The 28 centres across Canada employ about 250 staff members, of which 65 percent have a disability. As well, the centres rely on the support of over 1350 volunteers who contribute several thousand hours of support. Collectively, these centres generate over $35 million into the economy annually. These figures show the growing significance of centres in many communities across Canada.

There are many ways to understand the impact of a social innovation. Typically, funders want to see numbers of people served and outcomes or amount of change in people's lives. These are important factors to document when assessing change. However, innovations must also pay attention to the motivations and stories underlying the experiences of people who participate at the centres. Independent Living Resource Centres have learned that these subtleties can often tell us why a particular approach is working. These qualitative approaches are also useful in explaining unintended positive outcomes.

The impact of Independent Living Resource Centres can be understood by examining both research and evaluations of centre initiatives and by the stories and lived experience of consumers. In this chapter, we shall use both of these approaches to explore the impact of Independent Living on individuals.

Who Is Served?

Independent Living Resource Centres (ILRCs) serve a wide range of Canadians with disabilities. As community-based and consumer-controlled organizations, ILRCs strive to be responsive to the needs of individuals in the areas they serve. The initial leaders of the Independent Living movement tended to be people with physical disabilities. As a result, some centres primarily support people with mobility impairments. Funding sources also have an impact on who is supported at centres. The 11 centres in Ontario, for example, provide facilitation and resource support for a Direct Funding Project. The province-wide initiative only provides support to people with physical disabilities who require attendant services and who can direct their own support. This funding thus provides a service for a particular group of consumers.

At the same time, cross-disability is one of the cornerstones of the Independent Living movement. As a result, in many initiatives over the years, a much wider range of people is supported. An example of this is *Navigating the Waters*, a skills development and employment program that was delivered by 22 centres from 1997 to 2005. An evaluation of this project showed that almost 20 percent of participants self-identified with "psychiatric disabilities." Many other disabilities, including developmental disabilities and visual impairments, were represented among consumers of the program.

There is no typical pattern of usage at Independent Living Resource Centres. The statistics from ILRCs vary quite considerably, because each community that hosts a centre has its own approach to the specific issues in their community. Some centres, for example, have developed elaborate, well-used approaches to information and networking, while this core function plays a minor role in other centres.

There is also variety in terms of the types and quantity of services centres provide. In some cases, a centre may be the main disability player in town, while in other cases, the ILRC exists among a wide range of disability groups and agencies.

During 2005–2006, the Independent Living Centre of Waterloo Region had the following contacts with members and consumers who use their services: individual advocacy, 260 contacts; peer support, 320 contacts; and volunteers, 1190 hours. These numbers are typical of the amount of contact that centres have with their consumers. Several ILRCs, including the Vernon Resource Centre in British Columbia and the Thunder Bay Independent Living Resource Centre, report that their information and networking supports reach several hundred people each year.

How You Are Treated Really Matters

Communities can be welcoming and inclusive or they can be cruel and exclusive. Historically, citizens with disabilities have experienced exclusion and negative stereotyping. Research completed with Independent Living Resource Centres shows that people with disabilities are treated very well at these centres.[1] In fact, people report that they are treated much more favourably than in other human service settings. At ILRCs, people describe an overriding attitude of respect. One consumer quoted in the research reflects what many others said: "Here it is different, it's not like welfare. They don't talk down to you, they respect you."

People also report in this research that they do not feel labelled at centres. For many people, this is a profound difference from how they are treated in other human services. As one person said, "Here you are accepted for who you are as a person. I didn't have to prove myself, it wasn't an issue." Another consumer explained, "When I am at the Independent Living Centre, the world of disability vanishes."

Peggy Hutchison, principal researcher on this Independent Living research, says, "People seem to really embrace the IL principles of personal choice and control." Hutchison's research included interviews with consumers who have been intimately involved with a centre. People were asked to describe their experiences and any impacts that experience with the centre had on them.

Peggy Hutchison (centre) with Anna Quon and John Lord, CAILC AGM 2006

Hutchison's research with IL consumers identified three themes that reflect the way people are treated at Independent Living Resource Centres. First, people are treated as *valued citizens*. As one man noted, "Every time I go to the ILC, I feel like I am getting support. I am always treated wonderfully. I always feel complete acceptance as an individual."

Second, people are seen as *full contributing members of the community*. As several research participants noted, everyone at an Independent Living Resource Centre feels they have an important role to play. One woman explained: "I think a lot of people need to be involved where you can make a contribution and be part of a team. That's what I felt when I was at the ILC, like it was a real team."

Third, people are treated with *equity and fairness*.[2] This theme is reflected in many of the comments of consumers. One consumer noted, "They treat you equally…. They give a whole new look to what a social worker should be. They become your friend and work side by side with you. Their goal is independence and they are by your side until you are ready to fly."

In contrast, participants in these research studies report many negative experiences with other professionals in their communities. People often feel they are not treated with respect; they are not given adequate information, seldom asked their opinion, and often experience attitudes that are condescending. Because of the experiences that most research participants had with professionals, there appeared to be a healthy skepticism about all professionals, including those affiliated with ILCs.[3]

Impact of the Independent Living Experience

An exploration of Independent Living Resource Centres and their impact on the lives of individuals who are members and participants provides several interesting insights. From previous research studies and from stories gathered for this book, we have identified three interrelated stages that consumers experience: initial encounters with centres; empowerment through participation; and contributing by becoming a leader.

Initial Encounters With Centres: "Finding My Voice and Myself"

Many of the consumer stories we have gathered describe people's deepening sense of personal identity and confidence through understanding the concept of Independent Living and by participating with an ILRC. One woman in British Columbia put it most clearly when she said, "In my initial encounters with the centre, I began to realize that I was finding my voice and myself."

Chris Loscerbo knows how important those initial encounters with the right kind of support can be. When Loscerbo acquired a spinal cord injury in Winnipeg, a nurse recommended he apply for the Self-Managed Care Program thorough the Winnipeg Independent Living Resource Centre. "Independent Living," says Loscerbo, "opened up everything for me," in terms of thinking about living with a disability. "It's a place to go; it's a way to exist. It presents opportunities to you—if you want to work, it's there. If you want to educate the person that hires you, it's there. I'm glad the Independent Living movement's around…if it wasn't out there it would be a pretty dark and desolate place."

Chris Loscerbo's initial encounters with the ILRC in Winnipeg allowed him to become one of the first two people with disabilities to pioneer the Self-Managed Care Program in Manitoba. The Independent Living movement has also had an important effect on him personally. "I've come out of my shell," he says. Since moving to Vancouver Island, he's begun to coach girls' volleyball at both the elementary and senior level. He is now chair of the IL centre in Duncan. He acts as an ambassador for the Rick Hansen program, where he speaks to school groups and service clubs about living with a disability. He's also head of the local chapter of the Spinal Cord Injury Society.

Acquiring a disability later in life can be confusing and disempowering. Some years ago, Dan Freidmann experienced serious mental health issues and left his family. Freidmann explains that, "I lived in a group home for two years. During that time, life had no meaning to me. Everything was taken care of for me—medication, boarding, and food. Although I learned how to cope with the world again, I lost myself in the process. I became one of the consumers in the mental health system."

When Dan Freidmann discovered the Disability Resource Centre in Richmond, BC, he found the support he needed. Freidmann says, "The positive attitude, openness, and comfort offered there attracted me to come to the centre regularly and to keep coming.… I discovered different options in life, such as learning, volunteering, working with a team, being accepted as I am, all of which helped me take my life to the next level." Like many people's experience during their initial encounters with centres, Freidmann learned quickly about the essence of Independent Living. He stresses that, "I can now choose to participate in any activities in the community; I can build my own future. I feel needed and I have something to contribute. I was not intimidated by the grand idea of IL, as nobody really imposed that on me in the beginning. Nonetheless, I was introduced to it, being supported and practicing it to some extent before I was aware of it."

"Finding a voice" is both an individual theme and a theme for centres. Finding a voice means that individuals with a disability learn that they can express their needs, speak about their goals and hopes, and be critical of services that go against self-determination and community. The Niagara Centre for Independent Living in St. Catharines, for example, supports more than a dozen different peer groups for people with disabilities. These groups provide a safe venue for people to gather, dialogue, and support each other. James Davis, current chair of the Niagara Centre, recalls that his first experience with Independent Living was as part of a young adults' group. Meeting people who faced similar challenges was inspiring to Davis. "Growing up, I never really felt like I belonged," he says. "Sure I had friends, but no one I could really talk to about my disability. This group experience boosted my confidence level."

Many centre events reflect the power of this theme of finding a voice. The 2006 annual general meeting of Breaking Down Barriers, the ILRC in Collingwood, Ontario, is a wonderful illustration. About 80 people from all parts of the community gathered to celebrate Independent Living. The annual report shows photos of people with disabilities participating in all kinds of community activities. Conversation at every table included people with disabilities and other members of the community. The evening theme of "activity, growth, and independence" was expressed clearly by board chair Dawn Myers when she reminded people of the centre's mission: "Breaking Down Barriers will be a voice for Independent Living by promoting active participation of people with disabilities in the Georgian Triangle." With leaders from the city and the non-profit sector in attendance, this evening represented full citizenship and the honouring of diversity, and the voice of people who are claiming their rightful place in community life.

The Empowerment Process: Building Competence Through Participation

Research suggests that participation in Independent Living Resource Centres is empowering for people. Yet, we might ask, what does empowerment mean? And how do centres contribute to empowerment?

Empowerment is often used as a buzzword, usually meaning that the person has taken charge of their life. We often hear people say, "She's empowered!" There is also a body of research which describes the move from powerlessness to more control in one's life. In this sense, we can think of empowerment as a process, moving from powerlessness to participation and contribution.[4]

In Table 15, the stages of empowerment from one major research project are highlighted. These stages create a framework for understanding personal empowerment related to participation in Independent Living Resource Centres. Each of these stages is discussed below.

Table 15
Elements of the Personal Empowerment Process[5]

Experiencing Powerlessness	***Gaining Awareness***	***Learning New Roles***	***Initiating/ Participating***	***Contributing***
Social isolation	Acting on anger	Connecting with others	Joining groups	Being a role model
Service dependency	Responding to information	Linking with resources	Speaking out	Having influence
Limited choice	Responding to new contexts	Expanding choices/ opportunities	Expanding participatory competence	Increasing self-efficacy

Reprinted by permission from research completed by John Lord and Peggy Hutchison.

It is not unusual for new people who come to centres to be experiencing some degree of powerlessness. *At an Independent Living Centre, peers engage the person in dialogue, and it is here where the individual begins to have an awareness and understanding of their own power.* Consumers report that what helps at this point is deep listening and respect. People also notice that there is very little power imbalance with the people who are assisting them. As one man noted, "There is no sense that they know best." Often, information helps immensely at this stage, as the new person begins to learn about the choices they have in front of them. We can say that a centre creates a new context that expands awareness of possibilities. One consumer described the process this way: "When I came out of hospital I was very ill. The centre offered me personal and moral support. They were there for me when nobody else was. My family wasn't available at the time and the ILC literally became my family."

As people connect with others through peer support and link with new resources, they gradually learn new roles and begin to internalize Independent Living. Typically, people learn about rights and responsibility. One staff person noted, "If people are given control, they must also be expected to shoulder responsibility." In research completed at ILRCs, consumers mention that being part of a centre helps them to feel better about themselves. As one woman said, "Since I started going to the ILC, my family and friends say there is such a change in me. I am not as uptight. You know, when you become disabled, you wonder why you should wake up. I now say that if I couldn't get to the ILC in my wheelchair, then I would crawl there."

People talk at length about expanding their choices and opportunities because of becoming involved in an ILRC. It seems as if the peer and social aspects are an important part of this process. People are connecting with people who have "been through it" and testing out new possibilities and roles for themselves.

Valois Aubut found his connection with the *Centre-ressources pour la vie autonome: Région du Bas-Saint-Laurent inc.* (CRVA: Lower St. Lawrence Region Independent Living Resource Centre) very helpful to his citizenship development. With support from the people at the centre, who worked as an adjunct to those supporters who were close to him, Aubut was able to take the steps that helped him become independent, by living in a supervised apartment in Trois-Pistoles. Very satisfied with the efforts he made, Aubut gained the self-confidence he needed to achieve his goal of living on his own.

Patricia Pardo, executive director of the Calgary Centre in the 1990s, says that many consumers have been influenced by the Independent Living philosophy. Pardo says, "The IL philosophy changed my life and the way I understood myself and the way I reframed disability as an aspect of my personal and social identity. On a personal level, the impact was profound."

Dr. Patricia Pardo

Part of the reframing of disability relates to how people view their independence. In traditional views, when people have to ask for help or assistance with daily living activities, they are seen as dependent. As Hilary Wellard, an original board member of the Halifax Centre says, "Independent Living doesn't necessarily mean doing it on your own—IL has taught me that it's alright to accept help." Over time, Wellard and many other consumers have come to accept that it is okay to need help with personal care, making phone calls, meal preparation, and many other things. This insight about independence is a huge change in mindset for many people with disabilities. Once people realize they can have others assist them and still be in control of their own life, they can quickly internalize the principles of Independent Living.

Participation helps people develop their skills and abilities and is a key element and outcome of involvement with an Independent Living Centre. Research confirms that people acquire skills and achieve a sense of accomplishment when they participate in an Independent Living Centre.[6] In research with consumers conducted by Peggy Hutchison and her colleagues, people identify three ways that participation enhances skills and sense of accomplishment. First, volunteering is identified as a good way to acquire new skills. One research participant described how it works for many consumers: "Most of us come here to help run the centre. Ninety-five percent of us who come down here need to fill our time, to live independently, and to have our freedom of choice in what we want to do. It's rewarding because it allows us to live in the world that we aren't used to; now we're learning on our own."

Second, involvement in committee work helps people build new skills. One person summed up the experience: "For any of us who have worked on committees, it does make you feel part of something. It makes you feel like you can do something despite having a disability."

Third, participation in education sessions and peer support groups build skills to participate in the wider community. Consumers who were interviewed identified a wide range of skills they developed, including leading or facilitating skills, problem-solving skills, and writing skills. Other people reported that participation increased their confidence and self-esteem. Some researchers call this growing sense of confidence through participation "participatory competence."[7] Table 16 outlines the story of Joe Hearn from Winnipeg and illustrates some of these insights about participation.

Table 16
Participation: Joe Hearn's Story

I am 50 years young. I was born and raised in Winnipeg. I have had cerebral palsy since birth. In the fall of 1968, the decision was made to integrate some of us older students into a "normal school." Suddenly I was surrounded by students who did more than watch TV all day when they weren't in school. They talked about their part-time jobs, girlfriends, and long-term goals. On the other hand, I did not have a part-time job or a long-term goal. But I did have a girlfriend! Little did I know that she would be the catalyst that started me on the road to Independent Living and ultimately working for the ILRC.

Winnipeg has long had a reputation as being among the leaders in the Independent Living Movement. People such as Allan Simpson, Henry Enns, and Tony Mann were all working feverishly to promote the integration and full participation of people with disabilities in society. In the 1970s, they were instrumental in promoting the construction of "Ten Ten Sinclair," a fully accessible, integrated apartment building that would provide transitional housing for people with disabilities, enabling them to learn the skills that they would need to live independently before relocating in the community. I was unaware of all of this work that was being done, but soon I would find myself embracing it. The Independent Living movement would change my life forever.

My life at home had become unbearable. Alcoholism and my parents' disapproval of my girlfriend had driven me to tell my rehab counsellor, "I have to get out of here! I don't care where I go, even if I have to go to a nursing home, you have to get me out of here!" He suggested Ten Ten Sinclair, and before I knew it, I had the keys to my new apartment in my hot little hands and I was moving. The IL movement's impact on my life had begun.

It is now the mid-1990s. My high school sweetheart, who by the way also has a disability, and I are married. We have left Ten Ten Sinclair and successfully made the transition to living independently in the community. I have been unemployed for 15 years. So, I made it known that I would be interested in helping out with reception duties at the ILRC in an emergency. Soon I was volunteering eight hours a day, five days a week. I enrolled in the Self-Managed Employment Training (SMET) program, took some computer classes, and eventually became employed as the receptionist. I am now one of two Information and Referral Consultants at the Winnipeg ILRC.

I am presently in negotiations to enter a different model of attendant services, called Brokerage, which will provide my wife and me with even greater independence. So you see, the Independent Living movement philosophy and the Winnipeg ILRC have had a great impact on my life. It scares me to think about what life would have been like for me if the people who had the will and the foresight to drive the movement forward had given up. We must never give up.

Participation does not necessarily mean success in the traditional use of the word. Frank Joseph from British Columbia reflects on his experience with Navigating the Waters, the ILRC employment initiative. "It all started with my intention to build a business to secure the future of my children," says Joseph:

> I joined the Navigating the Waters project at our centre, and worked on the business plan with the Career Development Facilitator for over six months. It was both a challenging and exhilarating experience—I had a regular schedule to squeeze brain juice onto paper, I was motivated at times and discouraged at other times, and most importantly, I felt in control. Sometimes my mental state hindered my progress, but I know that my ability is not judged based on my mental illness. In the end, I decided not to pursue the business initiative. Some people may think it was a waste of time, but to me, the process itself is most beneficial, and the outcome is based on my own judgment and informed decision making. I consider this as the finest example of consumer control and empowerment in the IL movement.

Making a contribution is for many people an important part of their empowerment journey. Dan Lajoie from the Kitchener–Waterloo Centre is typical of consumers who contribute. Dan gave back to the ILRC by serving on its admissions board and various committees. He also worked for a stint in reception, where he was asked whether he could do web design. Though he'd never tried it, he answered, "Sure," and he credits the ILRC with motivating him to learn new skills that he continues to use today in his home-based web design business.

Similar to these findings on Independent Living Resource Centres, research on consumer-driven organizations in community mental health shows positive outcomes for individuals related to community participation and empowerment.[8] Consumers who participated in consumer-driven organizations showed more positive outcomes related to social support and participation in community activities than their peers who are not involved in such organizations. They also showed a significant reduction in days of hospitalization. This new research on consumer-driven organizations is demonstrating the value of autonomous peer-driven organizations across all areas of disability.

From Users to Leaders: Staying Involved by Contributing

Many people who begin their involvement with the Independent Living movement as users of services become leaders in the movement. Dave Martin from Winnipeg, a long-time leader within the movement, reflects on how experience with the Independent Living philosophy grows on you over time. “When I was young, I never imagined being able to live in my own apartment, pay my own rent, and have my own privacy,” says Martin. “The more I had the opportunity to do that, the more I became committed to the idea.”

Kelly Nadeau, CAILC board member from Calgary, says that people connected with centres develop a “contribution ethic” because Independent Living nurtures people’s strengths. Nadeau credits role models in the IL movement for his own development, and says that the very consumers he has supported have been his inspiration. He explains that, “Independent Living has given me a sense that I’m not alone.” And he advises, “Think not disability, think of ability.” It is clear from our research that people have been able to focus their empowerment journey on expanding their own strengths by contributing their own skills in service to others.

Many consumers say they became leaders because they were asked. Jim Davis, current chair of the Niagara Centre for Independent Living, recalls being invited to join the board of directors after participating in numerous groups over the years. Davis sat in on a board meeting to see if it would be something that he would enjoy. “During the meeting I felt I could contribute to an organization that does so much for the community,” says Davis. After being on the board for about a year, he became the chairperson. Davis describes how he has grown as a leader. “Being able to contribute to the Niagara Centre in such a large way has really boosted my confidence level. I am able to speak my mind and not be worried about what others think of me. This position has made me realize that I can contribute. It has also made me realize that everybody can contribute in some way if given the proper tools, and to me that is what the Independent Living philosophy is about.”

Table 17
Empowerment and Participation: Story From the Niagara Centre for Independent Living

During National Access Awareness Week, the Niagara Centre on Independent Living had people give testimony to how the Independent Living movement had changed their lives. There were three chairpersons for the event, one of whom had a developmental disability, who had never before been given the chance to speak in front of people. There was a crowd of about a hundred and fifty people and this young man was very nervous. When he stood up to chair the event, you could sense that people in the audience were sceptical. Yet, when this man spoke, it was so professional; nobody could have done better. Even his mother was astounded at the changes she saw in her son.

We often see the transformation of individuals once they have been given the opportunity to participate like that. People often ask, what can we do to assist? It is about enabling people and giving them a chance to develop their skills. This man could now be chairperson of any committee or board. He has developed his skills tremendously and has gone back to school. There are so many people who, two years ago, were afraid to come in, they were afraid to be with other people. And now it is to the point where they come in and tell us what they want and what they don't like. They make sure their opinions are known. They call us up, they write to our newsletter. It is really empowering to see the abilities…it is amazing to see people transform.

Being a centre board member has allowed some consumers to benefit personally while flourishing as leaders. Dave Martin remained on the Winnipeg Centre board for nine years, during which time he constantly advocated for housing and self-managed attendant services for people with disabilities. Martin's advocacy and persistence finally paid off. He explains, "In 1991, the government of Manitoba decided to introduce a self-managed attendant care program," and Martin was one of the first people with disabilities to take advantage of the program.

Under self-managed attendant services, consumers hire and manage their own attendants using funds allotted to them by the Manitoba Health Authority. "The beauty of the option is that it has given me much more control over the attendant services that I require to live in the community and be actively involved in employment, education, and leisure pursuits," says Martin. "It has definitely given me a sense of empowerment over my life even though I have what almost everyone would say is a very significant disability."

Some consumers who became leaders have made their presence felt in the development of an Independent Living Resource Centre. Dan MacLellan from Halifax played a key role in the founding of the Halifax Independent Living Resource Centre. As an entrepreneur, he understood the importance of building a unique place where consumer control would be understood and valued. MacLellan's journey to IL leadership was filled with lessons that he used to full advantage. His story is outlined in Table 18.

Table 18
Leadership and Contribution: Dan MacLellan's Story

Dan MacLellan always had a sense of adventure and innovation. In university, he found the solution to the problem of getting to school by borrowing money to buy an accessible van. A small branch of the Nova Scotia government's Department of Community Services agreed to lend the money to the Canadian Paraplegic Association, which in turn loaned the money to MacLellan to buy the van. "They took a big chance on me," he says. But the gamble paid off. Two weeks after he graduated in 1975, MacLellan was hired by the Nova Scotia provincial government.

"It was very, very unusual for a person with my level of disability to be out in the workforce," says MacLellan. "Everywhere I went I was bumping into 'We don't know' and 'We don't have a policy for that.'" But some people were accommodating, and as far as the few accommodations he needed went, "We just winged it," he says.

Dan MacLellan's commitment to innovation continued. Around 1990, MacLellan says, his needs for attendant services changed, and he began looking for a way


Dan MacLellan

to establish a Self-Managed Attendant Services program. He didn't think that any of the existing, disability-specific organizations offered the appropriate vehicle for such a program. Looking for a broader based, consumer-controlled disability organization, he discovered there were two in Halifax that were, in his words, "jockeying for approval" from CAILC to become Halifax's Independent Living Resource Centre. "That's when my view changed and I began focusing my attention on creating an IL centre in Halifax," MacLellan says.

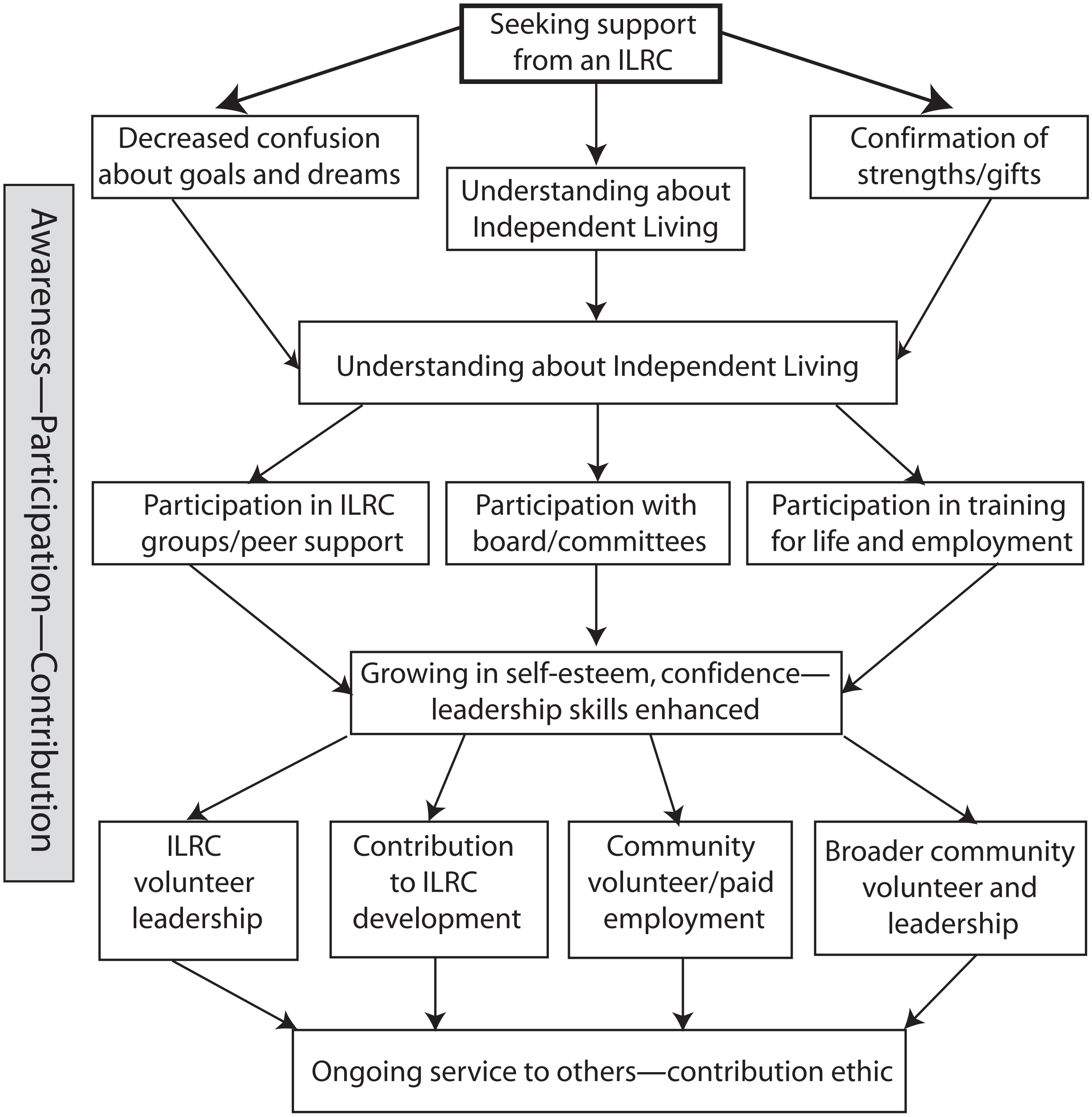
MacLellan joined both organizations as a member and joined both boards. "I became the go between and the mediator," he says. Eventually, at a meeting of the membership, consumers voted to approve the merging of boards to form a new organization. MacLellan was elected chair, with 50 percent board membership coming from each of the original organizations. Thus, the Metro Resource Centre for Independent Living was formed and the IL movement became firmly established in the Halifax region.

Today the organization has been renamed the Independent Living Resource Centre, Halifax Regional Municipality. Dan MacLellan spent ten years as ILRC Halifax chair, five years as CAILC chair, and is one of nine participants in the Self-Managed Attendant Services pilot project administered by the Halifax ILRC. MacLellan feels the pilot project and its participants have been instrumental in the provincial government's recent announcement that it will begin to offer its own self-managed attendant services program.

Independent Living is the philosophy that has guided MacLellan's personal and business choices as well as larger organizational ones. It's just "the way I live my life," he says. But the challenges to Independent Living are many. "Our lives are so much controlled and dominated by medical people," as well as by financial limitations and restrictions, which compromise the ability of people with disabilities to make choices around healthy eating, working, and even having a live-in partner. With Independent Living, says MacLellan, "You put the consumer in the driver's seat." Dan MacLellan's contributions speak volumes about consumers as leaders being an impact of Independent Living.

"Consumers as leaders" is a recurring theme within the Independent Living movement. Like other citizens, people with disabilities want to participate and contribute. Independent Living Resource Centres provide a vehicle for people to move from consumers to leaders. As we have seen, people contribute in all kinds of ways, including mentoring others, volunteering with the many tasks that need to be done at a centre, and participating as a board member or as a member of a committee.

Table 19
Impact of Independent Living: From Consumers to Leaders



For many people, what they learn at an Independent Living Resource Centre prepares them to participate and contribute to their community as an engaged citizen, as a neighbour, as a worker, and as a volunteer. Sue Morgan, current chair of the Independent Living Centre of Waterloo Region, is very involved in her community as a volunteer and as an active citizen. She sums up her experience by saying, "Independent Living has changed my life. Not only do I now feel personal confidence, I am able to do anything that I want to do." The contribution ethic of so many consumers speaks to the important role that centres play in supporting people to develop civil society skills.

Table 19 summarizes the insights gained from research and stories about how Independent Living consumers often become leaders. The themes identified here show that there are various paths to empowerment and leadership. While not everyone who participates in an Independent Living Resource Centre moves into a leadership role, this summary can serve as a template of possibilities for consumer empowerment.

Navigating the Waters: A Unique Initiative With Positive Outcomes

Until recently, the Canadian Association of Independent Living Centres (CAILC) did not track outcomes that resulted from the work of local centres. However, in the late 1990s, a multi-year service delivery contract from the federal government's Opportunities Fund made it possible for CAILC to implement and evaluate an individualized employment program called Navigating the Waters. Although the project officially ended a few years ago, several centres were able to keep it going as a main part of their work. This outcome signals that there were many positive gains because of Navigating the Waters. The project and the outcomes illustrate that tracking information across centres is a powerful way to assess the impact of Independent Living on individuals.

The goal of Navigating the Waters was to support individuals with disabilities to gain attachment to the labour force through either full- or part-time work. CAILC set several objectives, including:

- Establishing a career-development facilitation mechanism with a cross-disability focus;
- Collaborating with existing and emerging outreach employment services to individualize and enhance employment services;
- Partnering with employers to promote positive attitudes and break down systemic barriers;
- Working with employers, Vocational Rehabilitation Services, and other government departments provincially and federally to solve problems relating to job accommodation, mobility, technical aids, attendant services, and access for people with disabilities while they are at work.

The Navigating the Waters evaluation was designed to assess the effectiveness of utilizing Independent Living principles in supporting consumers to become attached to the labour force through participation in a variety of career development activities. As part of the evaluation, information was gathered in an ongoing manner, with quarterly reports throughout the project from career development facilitators and from participants. Researchers also gathered stories from consumers, completed focus groups, and conducted site visits to four centres. The evaluation results for 1999 to 2001 showed that:

- Twenty-one centres supported 1156 consumers in their career development path. Each centre had one or two career development facilitators whose role was to listen, help with planning and goal development, and link the consumer with appropriate community resources;
- The focus of each centre's work in Navigating the Waters was highly dependent on what other employment agencies were doing in their community with the purpose of complementing, not duplicating, existing services. In some communities, for example, Navigating staff did little job development, because another agency was already doing this for the community. This demonstrates the community focus of the centres and their capacity to build individualized supports in collaboration with community partners;
- People with disabilities who participated in Navigating represented a wide range of disabilities, with 19 percent self-identifying with a psychiatric disability, 15 percent with mobility impairment, and 5.5 percent with multiple

disabilities, and the other 60 percent representing a wide range of disabilities. These figures show that this program was truly cross-disability in orientation;

- Because most people had been out of the workforce for a long time or had never been in it, 50 percent of consumers chose pre-employment activities to help them focus on their strengths, dreams, and career goals. Thirty percent of participants used peer support groups as a way to deepen their understanding and confidence;
- Many consumers found that their career development explorations led them to specific training or education. Twenty-one percent took training courses for a specific field and another eight percent went to college or university for courses;
- Core programs of the centres were used to complement and support the career development process. Information and networking, a core theme area, was especially well used, with almost 70 percent of consumers taking advantage of this support. This finding shows that the centre programs function as a seamless approach when supporting individuals in their personal journeys;
- The facilitators within each centre were crucial to the job finding process. Fifty-one percent of participants met with their facilitator 1 to 4 times, while 31 percent met with the facilitator 5 to 9 times, and 18 percent met 10 or more times. People who found employment in any three-month period tended to be people who had met with the facilitator several times;
- The research showed that there is a gap between what people require for job support and what is currently in place. Seventy-eight percent of consumers, for example, identified workplace accommodations that they required, but only 22 percent were able to access such supports;
- Thirty-eight percent of consumers found or created employment during Navigating the Waters. This figure is higher than the national average for Government of Canada employment programs. Of those who found employment, 43 percent found permanent jobs, 40 percent obtained contract positions, and 17 percent became self-employed;
- Navigating the Waters contributed to other outcomes for participants. For example, 80 percent of people who became employed felt that their quality of life had improved, while 93 percent said their job had helped them

develop new relationships. In addition, most people who did not find employment indicated that the individualized career development process was a positive experience because it enabled them to build their skills or find volunteer involvements;

- Some consumers said that the Independent Living approach to employment enabled them to reframe their perceptions of career and employment. The story of François Roberts in Table 20 illustrates this theme.

Table 20
Using Independent Living to Reframe "Career":
François Roberts' Story

François Roberts had been very active in her profession. As an occupational therapist, she kept an intense schedule and thoroughly enjoyed her work. After becoming disabled, she had to give up her profession, which was very hard for her. "I felt like I had let my patients down, and I experienced a long period of isolation and impotence," she said. "When I came to the Independent Living Centre, it was as if I had closed one door, and I needed to find another. The centre has helped me to find that door."

In her profession, Roberts felt very controlling and controlled. With the IL approach, she discovered more about giving control away. She found this a paradox—that she could have a greater sense of self but more control even as she gave some away. "Independent Living is like native medicine," she claims, "working *with* the person, not on or for the person." For a long time, Roberts had refused to acknowledge that she had a disability, and since her professional association was not supportive of her condition, this reinforced her confusion.

As Roberts began volunteering at the ILRC, her confidence grew and her competence returned. She still uses many of the skills that she learned as an occupational therapist, such as facilitation, listening, and organizing. But she uses these skills within an IL framework that respects people's choice, and recognizes that the journey is as important as the outcome. Her volunteer experience has given her the confidence to begin to look for work.

To date, Roberts has had two job training experiences while continuing to do volunteer work at the ILRC. She is hoping that her next experience will enable her to call again on the support of Navigating the Waters. While utilizing many of the skills of her profession, she now hopes to work in a setting that utilizes the IL principles. She feels her own disability experience will be an asset.

Summary and Reflections

In terms of the impact of Independent Living on individuals, three themes emerge from the research and the stories of consumers: first, how centres are contributing to the empowerment and resilience of members; second, the power of the personal and political in the process of individual change; and third, the importance of creating conditions so that consumers can become leaders. These themes together demonstrate that opportunities for participation and contribution matter.

First, research shows that participation in an Independent Living Resource Centre contributes to empowerment and resilience. Extensive research on resilience over the last ten years has consistently identified three factors that enhance resilience: *caring relationships, high expectations, and opportunities for participation and contribution*.[9] The empowerment research we shared shows how consumers often connect deeply with centres. Often this begins with a relationship, usually peer in nature. Finding a peer who understands has been identified as a very important mentoring part of the empowerment journey. Centres by their very nature have high expectations. As we have seen, centres assume that people can make decisions, participate in their own life choices, and take responsibility for their decisions. Finally, centres provide opportunities for participation and contribution. As we have seen, there are multiple ways that people participate and contribute.

Second, this work helps us understand the power of the personal and the political. People connected with centres have many personal stories about change and citizenship. The narratives are often deeply personal and yet they are saturated with political realities. The person who comes to the centre in search of employment may not find the ideal job because the world of employment is not always welcoming of citizens with disabilities. The person who seeks a support group at the centre may find comfort in that setting, but still struggles with trying to survive on a limited disability pension.

The IL approach to individual advocacy is both personal and political. Citizens with disabilities seek redress for discrimination and related barriers. To be successful, consumers soon learn that it is not enough just to tell their story. They must become political, and learn to study and advocate for themselves against structures that may seem foreign at first. People who achieve positive outcomes have often had to speak up and demand their rights. The personal is political, a slogan of the women's movement, is well understood within Independent Living Resource Centres.

Third, centres create conditions to support consumers to become leaders. From the stories we shared, we can see that many consumers become engaged in a wide range of activities and leadership roles. In some cases, this happens quite intentionally as a consumer may be inspired to move toward a leadership role. In other cases, it happens without intention as a consumer is simply drawn to participate and in that process becomes involved in a leadership role. In either case, we can say that personal empowerment is often the result of consumers becoming engaged in leadership roles.

These themes together emphasize that opportunities for participation and contribution matter, and this is one of the strongest elements that explains the positive influence and impacts of Independent Living on individuals. Table 21 lists the main elements that give us this insight.

Table 21
Impact of Independent Living on Individuals

1. People with a wide range of disabilities are supported by the Independent Living Centres, even though some centres are more cross-disability oriented than others.
2. Positive initial encounters with Independent Living help people to discover their own voice and to gain personal awareness.
3. Research shows that involvement with an Independent Living Resource Centre has positive impacts for individuals, including acquiring useful skills, enhancing self-esteem, and becoming empowered.

4. Consumers describe the way they are treated with dignity and respect at ILRCs as a critical element that explains positive outcomes. This includes being listened to, accessing quality information, and experiencing good process for dealing with issues and problems.
5. Consumers themselves testify to the importance of the ILRC experience in helping them understand and address the political realities that impact on their independence.
6. Centres create conditions that enable consumers to expand their contributions, with many becoming leaders in the process. People contribute as volunteers, as board and committee members, and in the wider community as engaged citizens.
7. Contact with the Independent Living movement through ILRCs enables some people to develop a clearer understanding of the IL philosophy and movement, which enables them to contribute more fully.

Finally, a third-party evaluation of disability programs funded by Human Resources Development Canada recognizes that services based upon Independent Living principles are more effective than traditional professionally driven services. The processes that are utilized by Independent Living Resource Centres are seen as the impetus for positive outcomes. The evaluation report notes that “advocacy, support, and training services provided through Independent Living Centres have been documented as effective in providing support and skills development necessary to enable people to make effective use of support service programs and to make decisions about their own lives.”[10]

> *The idea of contribution is especially instructive because it lies in the area that unites the “I” and the “we.” We contribute because we are part of something larger than our own lives and efforts, but the form of our contribution is based in our uniqueness and our individuality.*
>
> —Carol Ochs, *Women and Spirituality*

Endnotes

1 Peggy Hutchison, Alison Pedlar, John Lord, Peter Dunn, Mary McGeown, Andrew Taylor, and Chris Vanditelli, "The Impact of Independent Living Resource Centres in Canada on People with Disabilities," *Canadian Journal of Rehabilitation* 10, no. 2 (1997): 99–111.

2 Peggy Hutchison, Peter Dunn, John Lord, and Alison Pedlar, *Impact of Independent Living Resource Centres in Canada* (St. Catharines, ON: Brock University, 1996), p. 13.

3 Ibid, 43-45.

4 Several studies have been completed on personal and community empowerment. See Charles Keiffer, "Citizen Empowerment: A Developmental Perspective," *Prevention in Human Services* 3, no. 16 (1984): 9–35; John Lord and Peggy Hutchison, "The Process of Empowerment: Implications for Theory and Practice," *Canadian Journal of Community Mental Health* 12, no. 1 (1993): 5–22; Ron Labonte, "Empowerment: Notes on Professional and Community Dimensions," *Canadian Review of Social Policy* 26 (1990): 4–75.

5 John Lord and Peggy Hutchison, "The Process of Empowerment: Implications for Theory and Practice," *Canadian Journal of Community Mental Health* 12, no. 1 (1993): 5–22.

6 Peggy Hutchison, Alison Pedlar, John Lord, Peter Dunn, Mary McGeown, Andrew Taylor, and Chris Vanditelli, "The Impact of Independent Living Resource Centres in Canada on People with Disabilities," *Canadian Journal of Rehabilitation* 10, no. 2 (1997): 99–111.

7 John Lord and Peggy Hutchison, "The Process of Empowerment: Implications for Theory and Practice," *Canadian Journal of Community Mental Health* 12, no. 1 (1993): 5–22.

8 Geoffrey Nelson, Joanna Ochocka, Rich Janzen, and John Trainor, "A Longitudinal Study of Mental Health Consumer/Survivor Initiatives: Part 2—A Quantitative Study of Impacts of Participation on New Members," *Journal of Community Psychology* 34, no. 3 (2006): 261–272.

9 Bonnie Benard, "Understanding Strengths-based Practice to Tap the Resilience of Families," in *Strengths Perspective in Social Work Practice*, 4th edition, ed. Dennis Saleebey (Boston: Allyn & Bacon, 2006).

10 Government of Canada, *Lessons Learned: Disability Policies and Programs. Final Evaluation Report*. Ottawa: Human Resources Development Canada, 1997.

Chapter 6

Influence of Independent Living on Communities: Building Connections and Capacity

In recent years, municipalities across Canada have been challenged to make their communities more accessible and welcoming for citizens with disabilities. This challenge for change has come from many sources, including disability activists, provincial legislation in some provinces, and from family groups. The 28 Independent Living Resource Centres have worked tirelessly with their communities and have had a significant influence on them. Although the central mission is primarily to work with individuals, centres have learned over the years that people's dreams and goals are usually embedded in community. Therefore, to have an impact on the lives of individuals, Independent Living Resource Centres address community barriers and build partnerships with others who are working for community change.

Understanding Community: Context, Activism, and Community Pioneers

In the early years of the Independent Living movement, there was little talk of community. Although one of the Independent Living principles was integration, much of the early focus was getting the core functions in place—information and referral, peer support, individual advocacy, and research and development capacity. Three major developments occurred in the 1980s and 1990s that moved community to centre stage in the Independent Living movement.

First, as centres implemented the principles and core programs, they became aware of the importance of context in the lives of people they were supporting. Information and networking, for example, turned out to be a rich community resource for people who were seeking support. It may sound trite to say that information is power, but when people receive information in a way that makes sense to them, it can be very empowering. Individual advocacy also proved to be very important in helping centres see the importance of context. Allan Simpson, one of the early leaders of the movement, often said that the role of centres was to support people to represent themselves and that this process required that we understand the context in which people lived. Simpson would encourage staff to slow down in order to understand people and their wishes to be part of community life.

As centres became aware of context, community took on more meaning and became a focus of dialogue. The links between personal goals and community possibilities deepened. If people are searching for housing, we need to discover who in our community is working on affordable housing. If people are searching for meaningful leisure participation, we need to discover the people and places in our community that offer inclusive, welcoming opportunities.

Centres over time have come to see themselves as mediating structures in their communities. When core functions work well at a centre, they build bridges for people with disabilities to become full citizens and contributors in their communities. As we shall see, this work has led to building partnerships with a vast array of community groups and organizations.

Second, disability activism began to demonstrate that advocacy was often necessary for communities to become more accommodating and accessible. Michael Huck's journey through the courts is a prime example of how disability activism actually increased awareness of community and its capacity to include or exclude people with disabilities. Huck's story in Table 22 shows how accessibility and accommodation became a critical community issue for the disability movement.

Table 22
Community Accessibility Means Accommodation: Michael Huck's Story

Disability activist Michael Huck went to a movie with his sister at the Coronet Theatre in Regina on May 16, 1980. The movie, he says, was terrible but it didn't really matter, because he was there to make a point. Theatre staff advised Michael, who used an electric wheelchair that he could either transfer to a theatre seat or view the movie from his wheelchair in an area in front of the first row of seats. Because of the nature of his disability, Huck was unable to transfer to a theatre seat, and even if he could, his safety would be in danger if there should be a fire. The second option was also unacceptable because there was very little space in the front of the theatre, making it difficult for him to view the movie.

Michael Huck's point was that he did not, in comparison to the non-disabled public, have an equal opportunity to view a movie in the theatre and that this clearly constituted discrimination against him because of his physical disability. It wasn't by chance that Huck ended up at the movie theatre that spring day. As a board member of the disability advocacy group Saskatchewan Voice of the Handicapped, he had fought for the inclusion of disability under the Saskatchewan Human Rights Act in 1979. "That legislation basically said you can't discriminate against people with disabilities in regards to accommodation, employment, access to goods and services, etc.," he says. But the legislation did not include a definition of accessibility. "We needed a test case, and that's where the movie theatre came in," explains Huck.

Michael Huck then launched a five-year court battle with Odeon Theatres. The Human Rights Tribunal ruled in his favour, agreeing that discrimination had occurred because the service offered by the theatre was restricted and inferior to that offered to the non-disabled public. Odeon Theatres appealed to the Court of Queen's Bench, which found that there was no evidence to infer that the theatre offered a movie and a place to view it, but that the offer was of a movie and a seat. Huck was offered the same service as anyone else and his failure to make use of this offer was the result of his inability, not the result of discrimination in the service. The Court of Appeal upheld the decision of the original board of enquiry. A summary of the findings reads, "In defining discrimination, the Court of Appeal finds that it is the consequences of the action of practices, not the motivation behind them which is important. Acts which are neutral on their face, which treat individuals in


Michael Huck

the same way, are nonetheless prohibited if they have the effect of continuing discriminatory practices."

Odeon Theatres appealed to the Supreme Court but the Court ruled it did not need to hear the appeal as it upheld the Court of Appeal's decision. The important victory to Michael Huck is that the case forced a definition of discrimination and accessibility. "The essential part means it's discriminatory to provide a service that's inaccessible to people with disabilities," says Huck. "Equal opportunity doesn't mean the same treatment."

Michael Huck's experience was the leading edge of community work that many disability activists were doing in the 1980s and 1990s. Huck is clear about the difference between the disability rights movement and the concept of Independent Living. The disability rights movement was "about monitoring programs and services to make sure they meet our needs," he says. "The IL movement was about organizing ourselves to provide the programs and services we need: when and how we needed them." Yet, these two movements have complemented each other," says Huck, "in terms of building an interest in community accessibility and the right to participate."

In reflecting back on community and the Independent Living movement, Michael Huck says, "The specifics of the issues have changed but the issues are still the same, including housing, transportation, employment, and accessibility." Like most disability activists, Huck's embrace of the IL and the disability rights movements was one of necessity. "Why did we get involved in these things?" he asks. "We had to. We didn't have a place to live, we didn't have jobs…" In addition, he adds, "There are still plenty of dragons to slay and windmills to charge."

By 1990, we see the third development that helped move Independent Living toward greater community involvement. There was a growing movement of pioneers pushing for a rediscovering of community. People like John McKnight, a professor from Illinois, were saying what we all knew—many citizens were isolated from community, and traditional service systems were keeping people from community participation and citizenship.[1]

McKnight and other leaders argued that in service systems, people learn compliance. In community, people come together around common interest. McKnight called these common interest groups "community associations," because it is where people gather to play, learn, and celebrate together. The literacy group, the women's group, the political group, or the recreation club—these are all places that accept diversity because people are together around a common interest, not around a disability. While Independent Living Resource Centres were clearly a consumer-driven enterprise, most were part of the non-profit sector, not strictly part of this new definition of community.

As this focus on rediscovering community gained momentum in the 1990s, the Independent Living movement was touched by these ideas. A 1991 Review of the Winnipeg Independent Living Resource Centre, for example, found that staff understood consumer control very deeply, but the Review recommended that staff receive staff training in community, especially related to better understanding community outreach and community development.[2]

Michael Winter, president of the National Council for Independent Living in the United States, attended the 1992 Canadian Independent Living Conference. He reminded delegates that, "Independent Living Centres need to understand the politics that are going on in the community, who the players are, what directions the community is going in." Winter added that it was critical for centres to be aware of their communities because, "Integration is the key to people with disabilities gaining power and access in the community." Winter encouraged centres to be a central part of their communities, and stressed, "If your community feels you are just a separate entity, existing for yourself and not wanting to contribute, or not wanting to understand what other people's problems or issues are, then you will end up being a separate entity."[3]

At the 1994 IL conference on "Progress Through Partnerships," John Lord, a researcher from Kitchener–Waterloo, challenged participants to make sure that consumer control was not the only characteristic to distinguish an Independent

Living Resource Centre. “Centres,” Lord said, “must be seen as full participants and full collaborators with the lifeblood of the community.” In terms of the importance of collaboration, Lord asked, “How many centres have thought strategically about how to engage churches, how to engage neighbourhood associations, or how to involve housing co-operatives in the process of enabling and supporting people to be full participants in community life?”[4]

The insights gained about community from these three sources (context, disability activism, and pioneers of community) have had an obvious impact. When two major studies were published on Independent Living Resource Centres in 1997 and 2004, it was clear that centres were well connected with their communities and, in many cases, were having an important impact locally and regionally. We shall explore these studies in depth.

Independent Living Resource Centres: Shaped by the Unique Issues of the Community

Each Independent Living Resource Centre is part of a community. The challenge has been to be responsive to the unique issues of their community while remaining true to the values and principles of Independent Living. Centres generally have done a good job in balancing these two directions. Leaders report that creating this balance involves doing what is right in the community and positioning their centre carefully in the community. When these two thrusts are coherent, centres maximize their community influence. Let us look at some examples.

For Independent Living Resource Centres, doing what is right in a community involves following the lead of consumers. In the early years of the Niagara Centre for Independent Living, input from members through community forums soon made it clear that transportation was a huge issue. For a centre that includes three urban and nine rural municipalities, it made sense that promoting more affordable and accessible transportation would respond to consumer needs. The Niagara Centre did have success with getting a regional transportation system in place called Mobility Niagara.

Similarly, other centres have followed the lead of their members in deciding how best to focus on their community. The Independent Living Centre of Waterloo Region became very involved in non-profit housing when its consumers identified housing as a central issue they wanted addressed. The Vernon Disability Resource Centre in British Columbia has added a range of programs over the years in response to consumers. They have also become *the* source of information for the Vernon region. In 1994, the Vernon Centre made 1800 contacts in the community, and by 2005, that number had grown to 16,003. The ILRC in Trois-Pistoles has initiated some significant employment initiatives in response to consumers. Since its inception in 1993, the Independent Living Resource Centre of Halifax has developed a number of demonstration projects in response to consumer need and demand. Each of these demonstration projects, such as the Self-Managed Attendant Services pilot, show how Independent Living can have an impact on a range of community issues.

Positioning a centre in a community has been an interesting process for leaders. One executive director commented that he did not realize how important positioning was until he became aware that his centre was often ignored in community planning efforts. Positioning of an Independent Living Resource Centre is influenced by several factors.

The image or profile of a centre in the community is key to positioning. All centres let their community know what they are doing and how they are doing it. However, centres find that they must approach consumers, service providers, and funders in different ways. Some centres admit they have struggled with legitimacy. A leader of a new centre said, “The service providers are the professionals in the community that have all the political power and I don’t know that we are recognized on their level yet as being a viable alternative. I mean, I hear a lot of approval for what we’re doing, but it feels like a pat on the top of the head.” Even though some centres would also be viewed as service providers, the fact that they are consumer-driven enterprises makes them quite different in the eyes of traditional providers.

Although centres indicate that their image and legitimacy have increased in their communities in recent years, some leaders note that there has also been a


CAILC and Montreal centre staff during a visit

perverted approach to Independent Living in some communities. In a study on the Ontario ILRCs, three centres identified attempts by other agencies to "jump on the IL bandwagon" without really changing the way they deliver services to be consistent with the movement's values.[5] Sandra Carpenter from the Toronto Centre has written that community services may attempt to associate themselves with the Independent Living movement without fully understanding the philosophy that drives it. As an illustration, Carpenter describes a rehabilitation hospital that runs a centre for technical devices and calls it an "independent living centre."[6]

Some centres describe their relationship with the wider community as being very positive. One executive director in Ontario thinks this success may stem from the consumer base that drives the centres. "I think we've had more success with generic organizations than the disability service providers have," she says. "Generic providers seem to be more willing to look at issues when they are brought by people with disabilities themselves, rather than by disability service providers."

Centres have learned over the years that community has enormous potential for individual empowerment and collective problem solving. In her recent book, *Shared Space: The Communities Agenda*, Sherri Torgman shows that communities by their very nature can lend themselves to collaboration.[7] The communities agenda, as described by Torgman, is primarily about promoting resilience in order to build strong and vibrant communities. The shared space of communities includes the space between citizens and organizations and the space between communities and government. According to Torgman's research, it is in these shared spaces that innovation can grow. It is possible to think of a vibrant Independent Living Resource Centre as an important shared space in community.

Community Connections and Influence

In a major two-year study entitled "Impact of Independent Living Resource Centres in Canada," Peggy Hutchison and her colleagues identified four areas where centres contributed to their communities and to the fabric of organizational life.[8] This research was based on a survey completed with 150 local non-profit organizations, informal groups such as self-help, and people who were on centre mailing lists in three communities. We shall outline the results of this study within each of those areas.

First, the study showed that most people surveyed were *familiar with ILCs*. On a five-point scale (ranging from "not at all" to "somewhat" to "totally"), participants indicated that their familiarity with the Independent Living Resource Centres ranged between *somewhat* and *a lot* (mean of 3.56). Participants' familiarity with the philosophy of Independent Living and self-determination was also quite high (mean of 3.80), as was their knowledge of centre core programs, especially information and networking (mean of 3.48), and peer support (mean of 3.13). Results showed that board and staff from other organizations tended to be more familiar with ILRCs than family, friends, and informal groups. It is clear from this study that centres are quite well known in their communities. This is confirmed by the centres themselves, which show how they are deeply embedded in their communities and widely connected with a range of other organizations.

Second, participants in this research indicated how they are *involved with the ILC in their community*. The results indicated that people are quite involved in their local centre: 83.4 percent of participants received the centre newsletter, 69.4 percent had used information and networking, 76.5 percent had referred people to the centre, and 52.2 percent had attended a centre event. It is interesting that next to information and networking, people were most aware of individual advocacy. Almost 50 percent of people surveyed indicated they were aware of someone who had obtained support from the ILRC who was unable to be served elsewhere in the community. Similarly, 57.9 percent of participants said that the ILRC had helped someone they know become more independent. This study confirms that individual advocacy of centres touches a wide range of citizens and organizations. As one research participant noted, “The centre seems to reach out to a lot of groups; they follow the concerns of the consumer and that naturally leads to community resources that can best address the consumer’s issue.”

Third, participants in this research identified *perceived impacts of ILCs on the community*. On a five-point scale, people rated centres highly in terms of being responsive to consumer requests (mean of 4.07). People also felt that the ILRCs effectively promote the Independent Living movement (mean of 4.20). In response to the question, “How well are the ILRCs meeting their cross-disability mandate, centres were ranked somewhat lower (mean of 3.54). Community members rated the impact of core programs in the following order: individual advocacy, research and program development, peer support, and information and referral. Staff members were seen to be effective and supportive of people with disabilities in terms of individual advocacy. Research participants felt that research and development projects had a sizeable impact on the community. As one person noted, “The community partnerships that are part of most research and development projects enable them to impact on individuals and organizations. People become aware of the IL philosophy and its potential.”

Finally, community members in this research study were asked to indicate the *extent to which the Independent Living Centre philosophy, leadership, and programs contribute to positive community impact*. On a five-point scale, the ratings were quite high. The IL philosophy was seen to contribute the most (mean of 3.95), with leadership next (mean of 3.79), and then programs (mean of 3.69). These three elements can be considered key levers for community change. The Independent Living philosophy has an impact on people and communities because it speaks to consumers in a way that makes sense to them. The philosophy by itself is obviously not enough; centres need leadership from staff and consumers to move the principles ahead. Finally, programs have an impact on a community when they are meaningful to consumers.

Peggy Hutchison, principal researcher on these research studies, has written that, “The ILRCs’ approach to supporting individuals is designed to have a ripple effect and through the process of individual and collective empowerment, ultimately lead to significant change in the community.” Hutchison adds that, “One of the key findings in these studies is that the ILRCs have impact because their work is done in the spirit of fostering fundamental changes." At the same time, Hutchison says, "Centres work hard to collaborate with other community agencies to create change by: forming partnerships; educating community groups; monitoring the community's sensitivity to disability issues; and encouraging people with disabilities to do community service."[9]

Centre Infrastructures Build Bridges to Community

As the Independent Living Resource Centres matured, they began to build effective infrastructure supports that deepened their connections with their communities. In many ways, these infrastructure supports are like mediating structures or bridges or shared space between the centre and the community. They allow people to access supports they need to be able to experience self-determination and citizenship.

Core programs at centres (information and networking, peer support, individual advocacy, independent living skills, and research and development) are part of the infrastructure. Core programs provide information, help with problem solving, support skill development, and connect people with a wide range of community resources.

In addition, centres have had the opportunity to create other infrastructure supports that contribute to community engagement. The following are four examples of such infrastructure supports.

Employment Initiatives: In the chapter on the impact of Independent Living on individuals, Navigating the Waters was identified as an effective employment initiative for consumers. When federal government funding for Navigating ended in 2005, several centres across Canada continued to operate the program. Many did this because they realized that employment and career development infrastructures were an excellent fit with their centre and with Independent Living. Some found funding from local federal government offices, including Collingwood, Thunder Bay, Vernon, and Richmond. Centres in Regina and Saskatoon utilized the Entrepreneurs with Disabilities program for those interested in self-employment, with funding provided through Western Economic Diversification Canada. The St. John's Centre and some of the centres in Quebec obtained provincial funding. This range of initiatives is quite impressive and shows how centres can build capacity when they need to. Centres realize that employment initiatives are an important community infrastructure. Of particular value are the employment facilitators who provide individualized support and links to employment possibilities in the wider community.

Direct Funding in Ontario: Leaders in the Ontario Independent Living movement played a central role in the development of the Ontario Direct Funding Project in the early 1990s. Vic Willy, executive director, realized that the Centre for Independent Living Toronto could have a major responsibility in implementing this new program. Because of Willy's leadership, in 1994 the Centre for Independent Living Toronto became the administrative body of the project, and the other nine centres in Ontario were funded to provide information and planning support for consumers who wanted to apply for direct funding. Having this unique initiative located within Independent Living Resource Centres has had many positive impacts on consumers and communities across Ontario. As one leader said, "Direct Funding and Independent Living are a perfect fit, and this infrastructure has created opportunities for self-determination and citizenship to be experienced in a very practical way." We shall explore the policy implications and influences of this development in Chapter 9.


Vic Willy, former executive director of CILT

Access to Adaptive Technology: Several centres have realized how valuable technology can be to people with disabilities. Centres in Richmond, St. John's, and Kingston, for example, have created welcoming spaces for people to access computers and adaptive technology. This technology is an important infrastructure support because it enables people to access the Internet, email, and other communication systems that are becoming common in our world. The St. John's Independent Living Resource Centre has also developed an outreach component so that staff can visit remote localities to support Internet access. We shall explore this development in Chapter 13.

National Projects Build Capacity: The Canadian Association of Independent Living Centres sponsors national projects from time to time. These initiatives have been very important in facilitating the capacity of ILRCs to build infrastructure supports. National Initiatives on Family Violence, Literacy, Crime Prevention, and Substance Abuse and Access to Recovery have all been designed to assist centres to work collaboratively with their communities. Because of these projects, centres have been able to develop partnerships with generic service providers in ways that have greatly enhanced the participation of people with disabilities in the wider community. We shall explore these national projects in Chapter 10.

Effective infrastructure supports enable centres to connect with the wider community, to create shared space for citizenship participation, and to develop partnerships that build community capacity.

"Creating What You Really Need": Community and System Impacts

Each Independent Living Resource Centre began its journey by identifying community issues of concern to citizens with disabilities. For most centres, this consumer participation is an ongoing process. It enables centres to have a good grasp of what people really need in order to build a good life in their community. Centres have become quite effective at creating resources and opportunities in their community in response to continuous consumer input.

The experiences and stories of Independent Living Resource Centres highlight several specific community influences. We identify initiatives from several centres to illustrate the types of community and system impacts across the country.

Accessibility: Several centres have worked closely with their municipalities to create resources for making communities more accessible. The Barrier Free Design Committee of the Collingwood Centre (Breaking Down Barriers), for example, regularly reviews site plans from the Town of Collingwood and makes recommendations about accessibility. One town councillor says this approach is very helpful to the municipality and assists the planning department in achieving better outcomes.

In addition, the Barrier Free Design Committee has created a "Thumbs Up" program. The purpose of the program is to promote accessible businesses in the Georgian Bay Triangle area. The committee visits businesses and completes a checklist of accessible features. If the location meets the criteria, it receives an accessible decal for its window. Other centres, such as Kingston, have created universal design concepts that are used to influence planners, professionals, and businesses. These types of accessibility initiatives are making communities more accessible and increasing awareness of the need for public and private sectors to work on this issue.

Supportive Housing: From its inception, members of the Independent Living Centre of Waterloo Region have been concerned with supportive, affordable, integrated housing. Over the years, the centre has made significant strides in stimulating and providing supportive housing for the region. The first project coincided with the development of the centre. The energy and advocacy required of the ILRC leaders created a strong commitment that other projects could be created. Two other integrated housing projects have been put in place since those early years. Consumers who have been surveyed describe high degrees of satisfaction with the housing options and the attendant support that is available.[10] Perhaps Jim Stuart, who moved from a chronic care facility, Freeport Hospital, to his own accessible apartment, can best describe the sentiment of those who have a real home:

> My very own place, my very own apartment
> My first everything, all the responsibility
> I will have to make my own appointments
> I will have to pay my own bills
>
> But I will have great freedom
> The freedom to come and go as I wish
> I will be able to have guests over
> I will be able to stay out if I wish[11]

Innovation and Independent Living: Centres have used research and community development to try out innovative ideas related to Independent Living. Research and development allows centres to develop consumer-directed initiatives in areas that may well fall outside traditional definitions of disability. These innovative projects have had impacts on local communities in three ways. First, they serve to broaden the population of people served by IL; second, they create awareness of the potential of the IL approach to resolve community issues; and third, research and community development provides a vehicle for consumers and communities to create meaningful projects that reflect their concerns. The following are some examples of positive outcomes of this innovation and Independent Living work:

The Ottawa Centre secured funding to work with transitional age youth. The staff worked with school boards to help them prepare youth with disabilities for their life beyond school. The centre reports that school boards have been very receptive to this IL work.

The Winnipeg Centre has had very positive outcomes with its PACE Project (Personal Attendant Community Education). This project has created a vehicle in Winnipeg for attendants to be trained by people with disabilities. Attendants say this training has prepared them to understand how to support the Independent Living approach. Over 90 percent of graduates from PACE find employment.

The Trois-Pistoles Centre used research on employment to raise serious issues about the impact of how people with disabilities are represented in the workplace. A recent study includes an action plan on ways to promote the inclusion of people with disabilities in the labour market. The study has been the focal point for discussion and action planning in the region.

The Opening Doors Project of the Halifax Centre was a pilot project funded by Corrections Canada. Designed to support federally sentenced offenders with disabilities as they reintegrate into the community, this project worked with 56 people. Staff, who acted as facilitators, provided resource support in a variety of areas, including information, housing search, peer support, locating education upgrading, establishing adequate transportation, and advocacy when necessary. A comprehensive evaluation at the end of the pilot project showed that Opening Doors was successful in achieving its goals and had a very positive impact on the lives of participants. The IL approach to the criminal justice system was also seen as very positive by organizations involved in the project.[12]

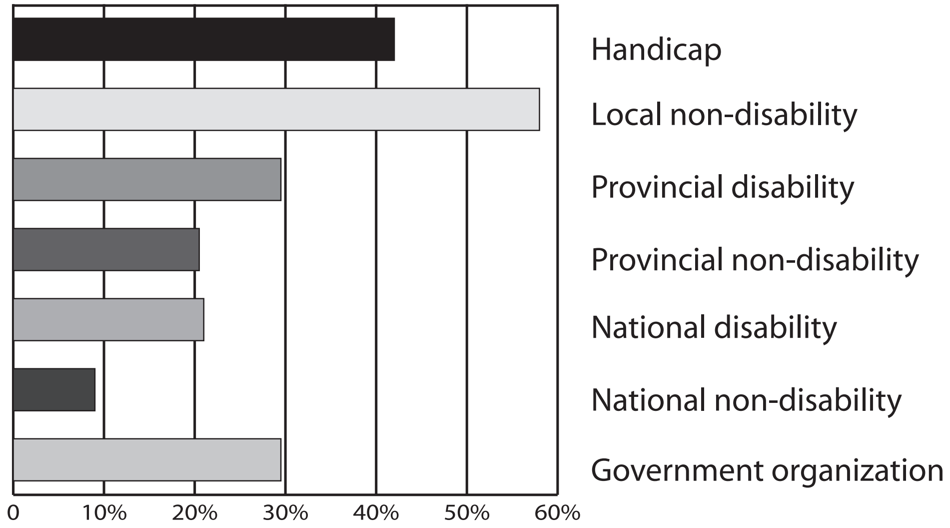
Partnership Building Contributes to Community Capacity

Independent Living Resource Centres have developed a wide range of partnerships with other organizations in their communities. The push to partner with others around common purposes was influenced in the 1990s by two developments. First, centres themselves were learning that in order to make integration and inclusion significant parts of their work, they had to build interest and capacity with other players in their community. Second, as research began the show the value of partnerships, the federal government started to expect projects they funded to work from a partnership perspective.

In recent years, several researchers and authors have described the nature of partnerships. Riane Eisler contrasts partnership approaches with domination approaches.[13] Certainly, people with disabilities are well aware of domination, and the widespread use of compliance and segregation. Some leaders in Independent Living say they approach partnerships carefully, because they know how quickly some organizations will try to take control of emerging partnerships. Eisler points out that genuine partnership is based on mutual respect. Others have stressed that partnerships must be based on common values and principles.[14] As we shall explore, some centres have also successfully used participatory action research as an approach that involves partnering with community groups and consumers.

In a recent study, "Role of the Consumer Driven Disability Organizations in the Non-Profit Sector," Independent Living Resource Centres identified numerous partnerships with other organizations.[15] The types of partnerships centres have experienced are outlined in Table 23. In this national study that looked at four consumer-driven organizations, it is interesting to note that CAILC's member centres reported the highest number of partnerships, when compared with other national initiatives. It is also noteworthy that the collaborations include disability, non-disability, provincial, and national partnerships. The highest number of partnerships were local, non-disability partners, at well over 50 percent.

Table 23
Partnership Projects of the Independent Living Resources Centres



Adapted with permission from Peggy Hutchison, "Role of Consumer-Driven Organizations in the Non-Profit Sector," 2004.

In this study, people talked about collaboration, connecting, networking, coalitions, and alliances. As one Independent Living leader interviewed said, "It has only been in the last ten years that there is a more collaborative process between consumer and service organizations." Similarly, a leader in a service organization said, "There is a feeling of solidarity where we have issues in common, including common advocacy agendas." People with disabilities and centres themselves are benefiting from community collaborations.

Insights on the nature and power of partnerships also emerge from CAILC's own information. During the preparation of CAILC's business case in 2004, it was discovered that member centres were involved in over 600 partnerships. On a national level, CAILC continues to develop a wide array of partnerships. CAILC currently partners with several other national disability organizations as well as public and private sector organizations. In 2006, for example, CAILC began partnering with the Council of Canadians with Disabilities and the Canadian Association for Community Living on a national initiative called "Ending Exclusion."

Similar to the research on partnerships—which shows that better outcomes result when people collaborate for change—centres have learned much about the

process of partnership development and how this can contribute to building the capacity of community.

- Successful partnerships *recognize the power of each partner and reflect a positive spirit of collaboration*. The strengths and assets of people with disabilities are honoured and utilized. Centres report that in their successful partnerships with other community organizations, people with disabilities are seen as participants and contributors. The collaborative spirit is captured in respectful partnership processes.
- Centres report that *relationship building is central to their successful partnerships.* Centres acknowledge that relationship building takes time and effort, and is nurtured by trust, open communication, shared values, and having fun! Relationships are also important because they are the beginning of each partner being able to share authentically, and speak in a "full voice."
- *Successful partners learn to work across differences and have a strong commitment to common goals.*[16] Centres have learned that working with differences is fundamental to reducing the mistrust that many organizations have when working with a consumer-driven group. Independent Living leaders find they must be clear about IL in a way that educates people, not in a way that alienates. Finding common ground is central to partnerships and to building the trust that can enable groups to work together really well.

Centre leaders we interviewed identified several ***outcomes*** related to effective partnerships. Each of these outcomes contributes to enhanced capacity of the community.

- *Successful partnerships reduce power imbalances*. We have noted that in some communities it has taken time for the Independent Living Resource Centre to be fully accepted by more traditional service providers. As centres build trustworthy partnerships, the ILRC becomes part of the fabric of community, and power imbalances experienced with other organizations begin to lessen. As a result, some centres report that their consumers are now more accepted in their partner organizations.
- *Successful partnerships enhance ongoing collaboration*. Partnerships by their very nature require a degree of collaboration. Some centres report that

effective partnerships enable them to collaborate with their partners on other significant issues. The Halifax Centre, for example, built partnerships with other employment agencies and did a lot of educating about Independent Living. When the community then began to collaborate around employment issues for the future, consumer control and related IL issues were central to the collaborative planning. Similarly, the Trois-Pistoles Centre worked with a number of seniors' groups and found that, over time, the groups began to use the principles of Independent Living in their work.

- *Successful partnerships increase participation and social inclusion.* Centres report that partnerships with generic agencies lead to increased participation and inclusion. A generic agency can be thought of as a community organization whose mandate is to serve *all* members of the community. Several centres, for example, have formed partnerships with literacy organizations. These partnerships have enhanced social inclusion in an interesting way. Initially, the partnership increased the conversation about inclusion between the IL centre and the literacy group. As the literacy group learns more about accommodation and other disability supports, they are able to provide support that people need to participate in literacy classes. In turn, as the IL centres learn more about literacy groups and their components, they are able to encourage and connect members to the local literacy group.

Summary and Reflections

Traditional service systems for citizens with disabilities have a very limited focus on community. In fact, critics of human services often lament the fact that disability support agencies frequently pay little attention to the vast resources of the wider community. As a result, research shows that many people with disabilities are lonely and isolated from community life.[17] Not surprisingly, centres report that many first-time users of an Independent Living Resource Centre lack information and awareness about the potential of community.

Integration was a first principle of the Independent Living movement. This principle meant that centres should design all programs and services to facilitate community integration and participation. In reality, some centres initially lost sight of this important goal and became focused only on programs. Yet, in the last decade, there has been a resurgence of interest in the potential of community. Research now shows that social support and community participation are both strong determinants of health.[18] In other words, people who participate in their community and have supportive people in their lives are much more likely to be healthier than people who have few relationships and limited connection to their community.

Independent Living Resource Centres have grown to be very connected with their communities. Centres spend a lot of time supporting consumers to participate and contribute to community. As research has demonstrated, this focus means that people from other organizations generally perceive that centres are having a very positive influence on their communities. Perhaps most interestingly, people say that the Independent Living philosophy has the most influence on a community.[19]

Given the innovative nature of the concept of Independent Living, this research finding is most encouraging. In terms of people with disabilities, the IL approach challenges services and communities to move from compliance to citizenship. Although centres find that some local agencies are resistant to the IL approach, more and more local organizations are embracing the principles of Independent Living, including self-determination, peer support, *and* integration. Table 24 summarizes how and why Independent Living Resource Centres are having an influence on communities.

Table 24
Influence of Independent Living on Communities

1. The interest in community within the Independent Living movement stems from three sources in the 1980s and 1990s: the awareness of context as central to people's lives; the impact of disability activism that addressed accommodation, inclusion, and related community issues; and the impact of community pioneers who were encouraging the rediscovery of community.

2. Independent Living Resource Centres learned that they could increase their influence in the community when they do what is right and position themselves in ways that enhance their image and legitimacy. In many ways, a centre's influence on a community is driven by its members and the issues that concern them.
3. The Independent Living Resource Centres have worked tirelessly with their communities and have had a significant influence on the way other organizations view disability. The IL values and principles as they apply to community services and programs have also had an impact well beyond the centres.
4. Centres are perceived by others to have an impact on their communities, particularly in the way they respond to consumers and educate others about Independent Living.
5. Centre infrastructure supports, such as the core programs and national initiatives, contribute to positive community influence and impacts. Infrastructure supports do this by serving as mediating structures or shared space between the person and his/her community.
6. Centres have built a wide range of partnerships with community groups and organizations. These partnerships have had three main influences and impacts: reduced power imbalances, enhanced ongoing collaboration among partners, and increased participation and social inclusion.

Partnerships have been a vital part of the community work that centres have undertaken. Centres enter potential partnerships with questions and interest, and use an Independent Living lens in their partnership negotiations. Centres have learned there are many elements to creating community partnerships, including building relationships, employing guiding principles, working with differences, and finding common ground. There are no shortcuts to partnership success! Centres consistently report that the community partnerships they create are having very positive influences.

There have been criticisms of the Independent Living movement for not focusing on community to the extent that it might. For some centres, this critique captures their preoccupation with programs and services. However, most centres are learning to use an Independent Living approach to connect with community and to build capacity with others who are interested in supporting people with disabilities to participate and contribute to community life. Overall, most centres are deepening their understanding of community and finding ways to make their partnerships have an impact.

Community connections are important for centres and essential for the well-being of consumers. People with disabilities grow in relationships when they experience the fullness of citizenship. With citizenship, people experience belonging. They also learn that they can participate with others to create a life of meaning. Community thus has a key role to play in the Independent Living movement. While community is not a panacea for solving the significant issues faced by people with disabilities, it is a strong foundation for citizenship.

> *Citizenship is a way of meeting one's deepest need, the need to belong; it gives voice and structure to the yearning to be part of something larger than ourselves. By the same token, citizenship is a way of making concrete the ethical commitments of care and respect, of realizing in action an obligation to aid fellow travelers.*
>
> —Mark Kingwell, *The World We Want*

Endnotes

1 John McKnight, *The Careless Society: Community and its Counterfeits* (New York: Basic Books, 1995). For further reading about the growing commitment to community that occurred in the 1990s, see David Schwartz, *Who Cares? Re-Discovering Community* (Boulder, CO: Westview Press, 1997).

2 Centre for Research and Education, *New Challenges: The Winnipeg ILRC in the 1990s* (Kitchener, ON: Centre for Research and Education in Human Services, 1991).

3 Michael Winter, "Independent Living Centres in the 1990s," in *Independent Living: An Agenda for the '90s,* ed. Aldred Neufeldt (Ottawa: Canadian Association of Independent Living Centres, 1993), 100.

4 For an extended analysis of the values and challenges of partnerships, see John Lord and Kathryn Church, "Beyond 'Partnership Shock': Getting to 'Yes,' Living with

'No,'" *Canadian Journal of Rehabilitation* 12, no. 2 (1988): 113–121.

5 See John Lord, Mary McGeown, Andrew Taylor, and Sherri Young, *More Than Just Another Human Service* (Ottawa: Canadian Association of Independent Living Centres, 1992), 75.

6 Sandra Carpenter, "The Role of Independent Living Centres in the Lives of Canadians: Colouring Outside the Lines," *Abilities*, Issue 7 (Spring 1991). 35-37.

7 Sherri Torgman, *Shared Space: The Communities* (Toronto: Caledon Institute, 2007).

8 Peggy Hutchison, Peter Dunn, John Lord, and Alison Pedlar, *Impact of Independent Living Centres in Canada* (St. Catharines: Brock University, 1996).

9 Ibid, p. 128.

10 Katherine Blaser, *Supported Housing Units Evaluation* (Waterloo, ON: Waterloo Region Independent Living Centre, 2004).

11 Quoted in Gary Nyp, *Reaching for More: The Evolution of the Independent Living Centre of Waterloo Region* (Kitchener, ON: Independent Living Centre of Waterloo Region), 95.

12 Chaytor Consulting Services, *Opening Doors Evaluation Report* (Halifax, NS: Independent Living Resource Centre, 2001).

13 Riane Eisler, *The Power of Partnership* (Novato, CA: New World Library, 2002).

14 John Lord and Kathryn Church, "Beyond 'Partnership Shock': Getting to 'Yes,' Living with 'No,'" *Canadian Journal of Rehabilitation* 12, no. 2 (1988): 113–121.

15 Peggy Hutchison, Susan Ari, Alison Pedlar, and John Lord, *Role of Consumer Driven Disability Organizations in the Non-Profit Sector* (St. Catharines, ON: Brock University, 2004).

16 See Kathryn Church's work on partnerships and their challenges, including Kathryn Church, *Forbidden Narratives: Critical Autobiography as Social Science* (Luxembourg: Gordon & Breach Publishers, 1997). Also see John Lord and Kathryn Church, "Beyond 'Partnership Shock': Getting to 'Yes,' Living with 'No,'" *Canadian Journal of Rehabilitation* 12, no. 2 (1988): 113–121.

17 Research shows that people with disabilities often experience more loneliness and isolation than other citizens. See F.M. Alpass and S. Neville, "Loneliness, Health, and Depression in Older Males," *Aging and Mental Health* 7 (2003): 212–216. Also see S. Hopps, M. Pepin, I. Arseneau, M. Freshette, G. Begin, "Disability Related Variables Associated with Loneliness Among People with Disabilities," *Journal of Rehabilitation* 67, no. 3 (2001): 42–49.

18 Social support as a determinant of health is highlighted in numerous studies. See, for example, Andrew Taylor, John Sylvestre, and Janos Botschner, "Social Support is Something You Do, Not Something You Provide: Implications for Linking Formal and Informal Support," *Journal of Leisurability* 25, no. 4 (1998): 3–13; Jack Styan,

Connecting to Citizenship: Social Policy Recommendations to Address Isolation and Loneliness (Burnaby, BC: Plan Institute, 2004); S. Cohen, L. Underwood, and B. Gottlieb, *Social Support Measurement and Interventions: A Guide for Health and Social Scientists* (New York: Oxford University Press, 2000).

19 Peggy Hutchison, *Impact of Independent Living Centres in Canada*.

Chapter 7

The Power of Peer Support: From Program to Philosophy

Peer support for people with disabilities established its roots after World War II, when many war veterans returned to Canada. The veterans with disabilities were determined to avoid the institutionalization that happened to disabled First World War veterans. In 1945, these veterans formed the Canadian Paraplegic Association (CPA) to fight the medical model that was entrenched in services and supports for people with disabilities at the time. CPA became a strong advocate for the development of community rehabilitation and other community supports.[1] Veterans wanted to avoid long-term hospitalization, welfare, dependency, and few job prospects. Soon, CPA branches sprang up across the country and war veterans began to support each other. This informal support took many forms, including counselling and support groups. This is seen as the formal beginning of peer support in action for citizens with disabilities.

Another important root of peer support originated in 1935 with Alcoholics Anonymous (AA), which operated under the principle that people who had experienced and overcome alcoholism would be more effective in assisting others who were trying to do the same. The AA concept of peer support was very democratic. All members were equal and a typical meeting included people from a wide range of socio-economic classes. What drew people together was a common condition, not any particular status. As AA grew in the 1950s and 1960s, its principles influenced other self-help movements that were beginning to take hold. The success of AA, and people learning from each other's experience and stories, became an important part of other peer support initiatives.

The Power of Peer Support as an Independent Living Principle

Peer support has been a vital part of the Independent Living movement since its inception. Early leaders understood that people with disabilities offer something to each other that professionals cannot offer.

Francine Arsenault, from the Kingston area of Ontario, was one of the pioneers of the Independent Living movement. After the 1981 United Nations International Year of Disabled Persons, Arsenault remembers striving to keep the momentum going. She explains that, "During the 1980s, advocates who had started this process realized we were going to need trained leaders in order to continue the work we had started. We went back to cities, towns, and villages and encouraged the formation of ILCs that would answer the needs of each community through peer support, information and referral, skills development, and research demonstration." Arsenault adds that, "Peer support was central to this work. People with disabilities would learn then to teach other people with disabilities how to become full participants in society."


Francine Arsenault

Allan Simpson, one of the founding leaders of CAILC, also understood that peer support was a fundamental principle that makes Independent Living unique and different from traditional human service agencies. Simpson believed there were potential leaders with disabilities all across the country—leaders with skills but with no vehicle through which to develop their potential. By developing Independent Living Resource Centres, Simpson felt that the movement created opportunities for those leaders to have voice and bring their leadership to others with disabilities. This "peer support mindset," as Simpson called it, has been central to the IL movement, and continues to be an important core function, program, and attitude at all centres.

CAILC defines peer support as a core theme of Independent Living Resource Centres:

> 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 basis and/or in a crisis, in an environment of mutual respect and trust.

Kathy Bloomfield, the first executive director of Breaking Down Barriers in rural Collingwood, Ontario, had many things to deal with in those early years, but found herself always coming back to peer support as the anchor to her work. Bloomfield would say that peer support is close to her heart and she knows personally how important it is. "Living out here in the rural area, it's harder to find each other," she says, "and consumers need the understanding they receive from other people with disabilities." The peer support program in Collingwood, which included a matching program and group work, "really drew a lot of people in—a real cross-disability group of people," says Bloomfield.

Kathy Bloomfield is currently helping people in the Collingwood area write their own stories about peer support and other Independent Living experiences. In one story, a consumer who had always been focused on her physical pain came into the centre and saw someone drinking with a straw and thought…I can do that. Bloomfield stresses that peer support is often like that. "It's a seemingly small thing that leads to so much more."

Bloomfield emphasizes that, "Peer support gives people self-confidence to take back some of their power that they have given away through medical intervention. Medical approaches often focus people on what they can't do, while peer support looks at what you can do—it is more hopeful." This perspective of peer support enables people to understand their own strengths and how to use them.

Table 25
Peer Support and Gifts

When visiting an Independent Living Resource Centre, one is often struck by the focus on people's strengths. Peer support probably personifies this "strengths perspective" more than any other work.

Each of us has strengths, whether they are reflected in our skills, talents, or interests. Some would say that each of us also has a gift, which can be seen as a deeper passion and strength that reflects who we really are. Regardless, peers who engage us in telling our story are almost instinctively looking for our strengths and gifts. As they listen, peer mentors also ask questions that enable us to discover our capacities.

A focus on strengths and gifts is a way of reclaiming an ancient, powerful idea. As Bruce Anderson reminds us, "In older times, elders in communities guided youth through initiation processes that were designed to help a young person name his/her gift."[2] This gift would then form the base of the relationship between the young person and their community. Over time, people would learn to understand their own gift, be mentored to use it wisely, and have opportunities to contribute in ways that stressed their strengths and gifts. Peer support that naturally or formally uses strengths as a core principle enables peers with disabilities to discover their gifts and to learn how to use them more effectively.

Imagine that you share with a particular group a certain life direction but that others in your life tell you it is unrealistic. One by one, each peer shares his or her story and experience of how they dealt with this direction you are considering. No one tells you what to do; they just share how they dealt with it. In this way, peer support has a kind of gentleness that is lacking in many conventional human services. This gentleness comes from respect that each person has for the other person's strengths and gifts. It also comes from the reality that peers understand the other person's experience. Because of this shared understanding, there is no need to justify, explain, or defend our perspectives and experiences. There is also a sense that seeing the struggles of the peer reminds us of our own struggles. This often elicits compassion for the struggle of the other person.

Listening and compassion come naturally to many people with disabilities. Bruce Anderson argues that this is because people's strengths and gifts are often related to the vulnerability and wounds they have experienced. Since many people with disabilities have experienced vulnerability themselves, they have learned to listen with compassion and are comfortable supporting others as they discover their own gifts.

Impact of Peer Support

The results of research on peer support are quite positive. The Peer Support Network of the British Columbia Paraplegic Association had a formal evaluation completed on its extensive program in 2003.[3] Participants who were part of the evaluation reported increased well-being from their participation in peer support. Research with GROW, an international self-help movement in mental health, shows that people can actually change their world view and increase their self-confidence as a result of peer group participation. This research also found that people who stay in a peer group for a longer time achieve better outcomes.[4]

A comprehensive four-year study, conducted by the Centre for Community Based Research and Wilfred Laurier University, shows that participation in peer support and peer-driven organizations has extensive benefits. In this study, active members with mental health issues showed a decrease in symptoms, while those in the non-active control group showed no change. Active members had a significant drop in the number of days they spent in hospital in comparison to the non-active control group where there was no such reduction. Most importantly perhaps, this study showed that active members significantly increased their social support and quality of life over an 18-month period.[5] A national research study on Independent Living Resource Centres showed similar positive outcomes for individuals. People who were connected with centres felt a sense of empowerment because of their participation in peer support interactions and activities.[6]

Kimberley McKennitt from the Centre for Independent Living Toronto sums up the power of peer support: "Independent Living is all about people knowing their own needs best and peer support is about people helping each other."

Furthermore, she adds, "Peer support is an IL principle because we value disability experiences, living with a disability, and the contributions people with disabilities make to their communities and society at large. Peer support is powerful because of the impact it has on the people involved. It can make a difference and even change people's lives. It promotes empowerment, validation, and compassion for the individuals involved."

Allan Simpson remarked that peer support is not just a program, but a methodology. Because the governance and service delivery models are consumer controlled, peer support is inherent to all aspects of an ILRC. Everything in the atmosphere of the centre is peer-support oriented, including the work of staff, committees, and the board of directors.

CAILC members gather—peer support in action!

Evolution of the Dimensions of Peer Support

Peer support within the Independent Living movement has its roots in peer counselling, a concept that was originally embraced by the IL centres in the United States. When Independent Living came to Canada, peer counselling was initially a core program. Peer counselling refers to one-to-one relationships between peers. The focus is on one peer sharing experiences, empathizing, and problem-solving with a less experienced peer.

The term "peer counselling" generated extensive analysis and debate within the IL centres in the early years. During an evaluation of the first three centres, it was noted that peer counselling was a term that few people embraced. One leader from the Calgary Centre interviewed for that study said, "I think the idea of taking 'counselling' out and putting 'support' in there is to take away from the counselling becoming very heavy duty." Peer counselling also received some criticism from professional counsellors about the ability of peers to engage in counselling. By the late 1980s, most centres referred to this core program as peer support.

Even as centres moved beyond peer counselling, most initially used peer support in a somewhat formal manner. In some cases, this meant training and supporting peer mentors, who would work with people on a one-to-one basis. In other cases, it meant organizing peer support groups. The story from the Thunder Bay Centre in Table 26 illustrates the history and evolution of peer support within an Independent Living Resource Centre.

Table 26
An Emerging Role for Peer Support: Thunder Bay Independent Living Resource Centre

---

The following story was written in 1992 as part of a review of the six Ontario centres. This analysis identifies some of the issues and challenges in the evolution of peer support and the role that consumer input can play in the process of change.

Shortly after the Thunder Bay Centre opened, it developed a one-to-one peer support program. The idea was that some consumers would be trained with specific skills and knowledge and would be matched with consumers who had a particular need or issue. As the program was getting underway, the centre held a series of open forums to get a feel for what consumers would be looking for in the peer support program. Consumers said that one-to-one matches were not that important. Some consumers indicated that training some consumers created an artificial hierarchy.

Based on consumer input and community requests, the centre decided to initiate support groups. There are now eight self-help and support groups that meet at the centre or another community organization. Staff from the centre help to facilitate the groups, assist consumers in getting public speakers, and provide support by sending notices of meetings. Staff encourage the members of each group to build their confidence and skill level so they can take more responsibility within their group.

Interestingly, as the support groups have evolved, one-to-one matches have begun to emerge as people realize they share common ground with another person. Thunder Bay staff and consumers now feel that the one-to-one peer support works most effectively when they emerge naturally out of a group context or with people knowing each other in some way.

Approaches to Peer Support

As peer support has evolved, it has been increasingly seen as a multi-faceted approach. Kimberley McKennitt from the Centre for Independent Living Toronto, says, "At our centre we don't *use* peer support, we provide opportunities through events, group activities, and workshops so that peer support can occur naturally and spontaneously. We also provide one-to-one support for consumers."

Typically, centres now provide a range of approaches to peer support, from formal programs to informal arrangements to one-to-one support and encouragement.

Formal peer support groups are facilitated by peers and focus on a wide range of topics. The Niagara Centre has a large number of groups, some focused on skills, and others focused on issues. Some groups are specific to the needs of a particular disability, such as a diabetic group. The idea of using peer support groups as a way to enhance skills and awareness has been expanding in recent years. Several centres, for example, have peer support groups for employment. This creates a safe space for people to meet and talk about their career goals and problem-solve ways to address employment barriers. Diana Smale's story in Table 27 illustrates the power of this type of peer support process and IL skills development.

Table 27

Redefining Personal Vision Through Peer Support: Diana Smale's Story

---

Diana Smale had worked in the secretarial field in her twenties and then stayed home raising her children for the next 20 years. In her late thirties, Smale began to develop significant hearing loss, and by the time she was in her early forties was facing all the challenges of a deaf person in our society.

When Diana Smale connected with an employment program at an IL centre, she was intrigued because it was the first time she had been involved with other persons with disabilities. She joined a peer support group on employment that involved people with a wide range of disabilities. Smale loved the peer group experience because, she says, "It made me bolder" and "changed my dream."

Having been trained in massage therapy, Smale now developed a vision of developing a clinic where she would work collaboratively with other professionals.

While Smale continued to pursue her dream, perhaps the important outcome for her from this experience was related to the power of peer support and self-growth. Smale benefited from the employment peer-support group so much that she decided to seek a peer support group at a Hearing Loss Centre. Smale said, "I am discovering what peer support really means; it is fabulous. It takes time to trust each other, but I am now discovering what it means to have hearing loss." Through peer support, Diana Smale is also gaining new confidence. She has discovered that with an acquired disability "you have to redefine yourself." She also stresses that the hearing world is rushed and that you have to negotiate your life differently.

Smale is now doing massage therapy a couple of hours a day and building confidence to pursue her larger dream. Of the employment peer-support experience, she says, "I didn't expect to get what I did. I feel grateful and hopeful. Hope is a good word to describe how I now feel."

It is important to emphasize that successful peer support groups are consumer driven. The Parenting with a Disability Network (PDN), sponsored by the Centre for Independent Living Toronto, provides peer support for parents and prospective parents. Kimberley McKennitt, coordinator of PDN, describes the peer support context: "It is the opposite of a traditional support group setting, in that there is no counselling service, no experts, and everyone is equal." This parenting peer support and networking group is facilitated, but it is modelled on a self-help approach in which everyone participates and all decision making is reached by group consensus. McKennitt adds that, "Guidelines created by the group are distributed at each meeting to ensure that the meeting is safe and inclusive. These guidelines allow participants to speak openly about the issues and challenges they face, knowing that what they have revealed will not be repeated or discussed outside the meeting space." Typical of most programs, attendant services, childcare, and other personal assistance are available upon request.

People also tend to self-organize into peer groups in more *informal ways.* As one executive director said, "What we have done is created a place where support happens in a natural way…like discussion groups. These informal gatherings are becoming effective because people are coming together and saying what they want. It has happened, I think, because we have been intentionally making a very egalitarian kind of atmosphere where peer support happens."

Other centres also report that peer groups often evolve naturally and informally. Kathy Bloomfield has observed over the years that, "People do tend to gravitate into groups and discuss an issue that someone is dealing with and others are sharing their experience." These peer connections often have a social component. For example, the Diners' Club at the Toronto Centre enables a consumer to choose a restaurant for a dinner with peers. Centres find that creating these informal arrangements stimulates conversations among peers. The Casual Friday peer group at the Collingwood Centre usually chooses a discussion topic but also has a social component. Kathy Bloomfield notes that these are generally very positive gatherings; however, she admits that new members often find it hard to fit in. This occurs because peers develop trusting relationships in their group and new members must find their own comfort level in the group. This usually happens over time.

Wendy Savoy, executive director of the Thunder Bay Independent Living Resource Centre, points out that peer support is the core program with the most variation. Savoy says this is mostly positive, but adds a caution: "When peer support focuses too much on the social, it can be segregating." She continues, "We think it is important for centres to work skill development and peer mentoring into the group process." Savoy and Bloomfield would both say that peer support coordinators must deal with how to maintain a safe space while remaining open and inclusive, and committed to the community integration principle.

Finally, centres continue to offer *one-to-one peer support*. Some of this happens when people seek information or assistance from staff. Since a majority of staff have some kind of disability, this connection is often a form of peer support. Centres report that they also very intentionally connect people with the most appropriate staff person. The following story is typical of the process:

> A new consumer with an acquired spinal cord injury was searching for more information from an ILRC. This person was connected with a staff person with a similar disability. After a long conversation, the new consumer was directed to a local peer support group at the Canadian Paraplegic

> Association. The staff person also agreed to meet with the new consumer on two more occasions to share ideas and do some longer-range personal planning together.

One-to-one peer support at some centres involves matching people with similar needs. These centres keep a roster of people who are interested in being peer mentors. Centres generally do not train these people, but staff may join the two peers for their first meeting to help them develop some ground rules and goals for their partnership. Quite frequently, one-to-one matches occur informally through other activities, where two people meet and realize they share a common concern or interest. As we have seen, this was the case in the Thunder Bay story. Occasionally, centres get a request from someone with a rare condition or situation asking for a peer. In those cases, staff will do their best to find someone who can play that role.

The Peer Support Process

There does not appear to be any well-documented process of peer support and it is surprising that there is little research to date on this important question. This may be due to the fluid and individualized nature of peer support. From conversations and observations we have had with consumers and centres, however, it is possible to suggest four phases in the peer support process that many consumers seem to go through.

First, a consumer is *seeking answers* to questions or concerns. Rarely does a consumer ask for a peer relationship, but there is something in the way questions are asked that often precipitates a peer-support response. One woman who accompanied her husband to a centre said, “He had a million questions, and they knew how to reach out and support him.” A staff person may recommend a peer support group or may connect the person with a peer.

Second, a *relationship is formed* with someone who can share information, ideas, or an effective process. Sometimes this relationship is with a peer mentor, other times it is with a peer leader of a support group, and may even be with a peer within a peer support group. This relationship appears to be central to the confidence building that is often part of peer support. As we have explored, the peer relationship is centred on strengths and gifts, accompanied by listening and compassion. The peer relationship enables the person to gain awareness and knowledge in a safe space.

Third, the *consumer acts* on some of the lessons and awareness gained from peer support relationships. One woman quoted in a study on peer support described her actions and changes: "After I started with the ILC, things just began to fall into place. I started going to their peer support groups and I became more confident. I just started saying what I thought. That is what they wanted us to do, so that's what I did…. There are so many groups at the ILC that you can learn to talk." This woman's experience is a powerful example of how peer support can nurture voice and sense of personal power. For most consumers, acting on their peer experience means becoming more active in their community. Peer coordinators mention that increased community engagement is one important marker of successful peer support.

Fourth, the consumer feels confident enough to act in the *role of peer mentor themselves*. One person commented, "I came needing support, and after feeling better about myself, I am ready to give my support to others…a full-circle experience." This final step can actually begin early in the process for some as they engage in a peer relationship where they are encouraged to voice their experience and insights. Table 28 highlights peer support principles developed by the Canadian Association of Independent Living Centres.

Table 28
Principles of Peer Support
Canadian Association of Independent Living Centres

- 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.

- Peer support encourages people with disabilities to speak with others and share their thoughts, concerns, and hopes with each other, and promote exchanges and discussion between individuals who have lived the experience.
- Centres provide peer support that promotes integration and participation in the larger community.
- Peer support encourages people to face new and possibly challenging situations.

In many ways, the experience of peer support within the Independent Living movement is one of mutuality and respect. Peer mentors are not teachers as much as they are experienced friends. Many consumers talk about the value of peer support and how it adds to their ongoing process of support.

The story of Meenu Sikand in Table 29 shows how peer support is woven into her life. In a way, the threads of peer support contribute to a more textured life. Sikand is a leader in the Independent Living movement and lives in Toronto.

Table 29
Peer Support Woven Into a Textured Life: Meenu Sikand's Story

Growing up in a small city in the north of India, Meenu Sikand says she had never seen anyone who used a wheelchair. But in 1986, three months after immigrating to Canada in her early twenties, she sustained a spinal cord injury that dramatically altered her life. To Sikand, who spent 10 months in hospital and rehab after the injury, the future looked "unknown and kind of dark." "I didn't know people with disabilities could have a productive life," she says. Sikand keenly felt the absence of her extended family to rely on for support. "That cultural aspect, the interdependency of the family, was not understood 20 years ago in Canadian society," she says.

It was when travelling on Toronto's accessible bus service that Sikand would meet a peer who listened to her express her dreams for the future and frustrations with living in a world not geared toward people with disabilities. That friend told her about a group of people with disabilities that met monthly. "We talk about the same things—we call it the Independent Living philosophy," she explained. Sikand would soon join them. "I met more people who were like-minded," she says. "It was just like having another family." That new family would become the foundation for the Centre for Independent Living in Toronto (CILT). Meenu Sikand chaired its board until the mid-1990s, and says she's seen the IL movement grow in sophistication and professionalism while still connecting to its grassroots. Sikand encourages peer support at every opportunity.

Meenu Sikand with son Manuv and husband Jai

Peer support did not end for Sikand with her introduction to the Independent Living movement. Sikand was led to human rights and advocacy work by Catherine Frazee, a board member of CILT and a well-known human rights activist. "Speaking with her gave me more insight into human rights for people with disabilities," says Sikand, describing how peer support led her to advocacy work. "As the chair of CILT, I felt strongly that we had to stand by other groups that do political advocacy," she says. "I have never been afraid of talking to my friends with disabilities about anything. They may not understand but they will show compassion."

Another issue that Sikand has brought to the consciousness of the disability community is that of mental health. She experienced post-partum depression after the birth of her son, and says it took a year for her to recognize the symptoms. When she opened up to her friends with disabilities, she says they began to share their stories with her and she realized that mental health was a huge problem that the disability community wasn't talking about. "We are not seen as a whole person so we're more vulnerable to depression," she says. "That was not recognized within our community." Because of peer support, says Sikand, "I felt I wasn't isolated, but it gave me a strong desire to discuss this issue," both among the disability community and the wider society. In 2002, she spoke at the second Parenting With a Disability conference held in Berkeley, California, and has written a number of articles that have been published in Canada, the UK, and the US. "It has made me quite aware that [mental illness] affects one in five Canadians and this number is perhaps triple for persons with disabilities," she says.

Bringing awareness of gender and ethnicity to the Independent Living movement, and bringing IL to women's and ethnic organizations, Meenu Sikand continues to be something of a bridge-builder between communities. Every day, she says, she strives to share ideas, and to become "a better person." "Each individual needs to take responsibility at their level then seek collective action," she says.

Recently, Sikand has changed from a career in IT to one as an Accessibility Planning Specialist for the Region of Peel, where she feels she can make a bigger impact by influencing public policies to create inclusive and welcoming communities. And there is still work to be done, she says. She participated in a Women's Institute on Leadership and Development in Oregon some years ago, which improved her skills in writing, public speaking, and media relations, and provided her with a network of women leaders around the globe. "I learned through peers that even in our own disability movement, women's needs are not recognized," Sikand says.

Today Meenu Sikand is an example of a woman with a disability who is making a difference in the Independent Living movement. She dreams of "the day when we don't need advocacy" because all Canadians have what they need. Moreover, she's an example to her own able-bodied son, who is now aware of the importance of disabled parking spaces, and of accessible washrooms at his school. Sikand laughs about the times her son has, to her embarrassment, pointed out someone who appears able-bodied using a parking spot reserved for people with disabilities. "It's challenging but rewarding," Sikand says. "That's one of the nice things about being a disabled parent."

Summary and Reflections

Four women recently shared their experiences about their involvement with Independent Living Resource Centres. Their conversation deepens our understanding of the power of peer support. As the conversation began, the women politely described how valuable it had been to connect with an IL centre and how useful the staff had been. As one woman described her experience, the room fell silent. "I had hit a wall and the coordinator suddenly opened up possibilities." She hesitated, "But, I still think I shouldn't be here." Slowly, another woman spoke very quietly and deliberately. "It is difficult and sometimes painful to admit that we need help and that we are worthy. I know; I have been there."

The first woman started to cry as she looked around the room and saw the faces of the other women. There was love and understanding in each pair of eyes and she clearly felt it. "I have never been involved in anything like this, I live such an isolated life," she said. A third woman began to describe her experience in coming to the centre. "I came to look for a job, but as I got to know the process at the centre better, I am now trying to discover what I want to do. I am really reaching out to myself and the ILC is helping me to do this."

The oldest woman in the group then described how important the peer support groups were for her. "I realized after being here for a while that I really wanted to be employed in order to connect with people. The peer support groups have given me confidence to begin to work again. It is one of the ways that I meet people." The first woman who spoke said softly, "I think I'm feeling better, just to know that you all understand what I am experiencing."

Peer support within Independent Living Resource Centres has evolved over the years from peer counselling and one-to-one peer support to peer support as a philosophy and methodology. Today, most centres have organized peer support in multi-dimensional ways. This means that peer support groups are available along with informal opportunities where peers connect with each other, informally, in groups, or in one-to-one situations. Staff members play a crucial role in facilitating peer support and acting as peer mentors.

It is useful to reflect on peer support within the context of the values of the Independent Living movement. The equality rights movement in Canada has been a huge part of the history of the disability movement. As we explored in earlier chapters, this involved a fight for equality rights, inclusion, and full citizenship. These social change efforts are reflected in the Independent Living movement, with its focus on full participation, consumer direction, and integration. How does peer support reflect these larger values?

In many jurisdictions, peer support has created safe spaces for people to meet and dialogue. Within Independent Living Resource Centres, this has taken many forms, including peer support groups, one-to-one mentoring, and more informal arrangements for peer connections. But in some cases, peer support has led to segregation from the wider community. Sometimes this has happened unintentionally. An example would be an informal group that meets for recreation purposes and then, over time, adds other segregated recreation opportunities. Another example occurs when a centre creates a peer support drop-in, and before long, it has become the only place that people with disabilities use for their community participation.

The reality is that sliding into segregation can happen very easily in a society that so readily congregates people with disabilities. Centres are becoming aware of the need to safeguard peer support principles to avoid this segregation trap. Three safeguards are emerging. First, some leaders say that peer support needs to be asserted as a vehicle for community engagement, and for centres to be clear that their purpose is to enhance integration and inclusion. Second, centres and CAILC have developed principles to guide peer support. These principles are providing a strong sense of understanding for implementing principle-driven peer support. Third, centres are paying attention to right relationships, both in terms of peer support leadership and in terms of volunteer leaders. This means that the right people must be in the right leadership positions for peer support to be successful. Right relationships and right principles work in tandem as safeguards. Table 30 outlines the evolution, benefits, and challenges of peer support within the Independent Living movement.

Table 30
Peer Support Within Independent Living Resource Centres: Evolution, Benefits, and Challenges

1. Peer support has been a principle and core function of Independent Living Resource Centres since their inception in Canada.
2. Peer support within the Independent Living movement began as peer counselling and was centred in one-to-one relationships.

3. As peer support evolved, it took on different functions and forms. Centres began to see peer support as a central philosophy and principle that guided everything they do. Formal peer support groups have been a very important program at some centres. More informal peer support groups are also part of most centres, and are often social in nature. One-to-one peer support and mentoring is also utilized by staff and volunteers.
4. Consumers and centres report that peer support has many benefits, including increasing self-confidence, building knowledge and awareness, and expanding a sense of empowerment. These reports are consistent with research that has been conducted on peer support across various areas of disability.
5. Peer support continues to face challenges within the Independent Living movement. It is often difficult to obtain funding for peer support, and so training for peer support leaders is often limited. The Canadian Association of Independent Living Centres has recently developed principles and guidelines to assist centres in implementing peer support. Such practical support should assist its further development.
6. Safeguarding the principles of peer support has also been a challenge. Centres have been exploring two safeguards for peer support: first, the importance of having well-understood principles that are fully implemented; second, paying attention to right relationships, both in terms of peer support leadership and in terms of volunteer leaders. Right relationships and right principles work in tandem as safeguards.

Peer support as a cornerstone of Independent Living shows promise for continued growth and success. In an aging society, more and more citizens will acquire disabilities. Peer support within Independent Living Resource Centres can offer significant support to citizens who are struggling to accept their disability or learning how to manage their situation. Peer support as a philosophy grounds ILRCs in people's lived experience, and ensures consistency with the dreams and goals of citizens with disabilities.

> *There is a generosity of spirit that one feels with self-help… Katherine Ashenberg, in her book* The Mourner's Dance, *suggests that it may be part of an ancient ritual. She points out that in primitive societies, a distressed or troubled person was often ordered to make a meal or do some other good work. Members of self-help groups tell us they often feel their suffering lessens when they participate in helping others who are struggling…*
>
> —John Lord and Peggy Hutchison,
> *Pathways to Inclusion*

Endnotes

1 Aldred Neufeldt, "Disability in Canada: An Historical Perspective," in *In Pursuit of Equal Participation: Canada and Disability at Home and Abroad*, eds. Henry Enns and Aldred Neufeldt (Toronto: Captus Press, 2003), 22–79.

2 Bruce Anderson, *The Teacher's Gift: Discovering and Using Your Core Gift to Inspire and Heal* (Vashon, WA: Island Press, 2006).

3 For a complete overview of the Peer Support Network evaluation, see L. Romilly, *Peer Support: Building Individual and Community Capacity: Evaluation of Two Smart Funded Projects* (Vancouver: British Columbia Paraplegic Association, 2003). The website of the Peer Support Network is [www.peerzone.org].

4 M. Kennedy, *Becoming a GROWer: Worldview Transformation Among Committed Members of a Mutual Aid Group* (doctoral thesis: University of Illinois, 1995). Also see, M. Kennedy and M. Humphreys, "Understanding Worldview Transformation in Mutual Help Groups," *Prevention in Human Services* 11 (1994): 181–189.

5 For a summary of this research, see Centre for Research and Education in Human Services, *Summary Bulletin: A Longitudinal Study of Consumer/Survivor Initiatives in Community Mental Health in Ontario: Individual and System Level Impacts* (Kitchener, ON: Centre for Research and Education in Human Services, 2004), 4. This study was part of a larger research initiative that examined the effectiveness of community-based mental health services. For an overall summary of that larger initiative, see "The Community Mental Health Initiative," *Making a Difference* (Toronto: Canadian Mental Health Association, Ontario Branch, 2004) [www.ontario.cmha.ca/cmhei].

6 P. Hutchison, A. Pedlar, J. Lord, P. Dunn, M. McGeown, A. Taylor, and C. Vanditelli, "Impact of Independent Living Centres in Canada," *Canadian Journal of Rehabilitation* 10, no. 2 (1996): 99–112.

Chapter 8

Making a Difference: The Power of Individual Advocacy

Each Independent Living Resource Centre creates a place where citizens with disabilities can explore possibilities. Similar to other centres, the Calgary Centre's mission states, "We believe in the right of people to equal opportunity, accessibility, and full participation in the community." To realize this mission and address the rights and possibilities of their members, centres have long established individual advocacy as one of their core programs. A brief look at the history of advocacy will help us understand the unique role that individual advocacy plays in the Independent Living movement.

Advocacy has long been associated with disability. In 1886, the Ontario Association of the Deaf (OAD) was formed, making it one of the first advocacy groups in Canada. In 1918, two other advocacy organizations were founded by professionals, the Canadian Mental Health Association and the Canadian National Institute for the Blind. The founding of the Canadian Paraplegic Association (CPA) in 1945 enabled people with physical disabilities to advocate on their own behalf. War veterans with disabilities were determined to be part of society, and CPA set up branches across the country that provided peer support and advocacy.

By the 1970s, when human rights were seen as central to social change, a wide range of groups of citizens with disabilities began to emerge across Canada. These networks of consumer groups rejected the medical approach to disability and asserted that equality, full participation, and social justice were the key issues to address.[1] The Coalition of Provincial Organizations of the Handicapped (COPOH), now the Council of Canadians with Disabilities, was formed in 1976 and remains one of the most significant national advocacy groups led by and for people with disabilities.

Like the Council of Canadians with Disabilities (CCD), most of the history of disability advocacy can be considered collective advocacy because it involves group action to impact change. As we have seen, collective advocacy was vital to the redefinition of disability, to the expansion of rights, and to improvements made in service systems across Canada. In addition to collective or systemic advocacy, there are three other kinds of advocacy—self-advocacy, individual advocacy, and agency advocacy. Table 31 highlights the four types of advocacy and some of the strengths and limitations of each.

The traditional definition of advocacy is "to plead the cause of another." Although this legalistic definition is obviously limited for the purposes of Independent Living, it does describe the essence of individual advocacy. We can also think of advocacy as a depth of feeling and commitment in advancing a cause. Advocacy is much more than education and usually goes beyond the call of duty. Advocacy stresses vision, choice, and voice. Pat Deegan, a mental health advocate in the United States, emphasizes the role of advocacy: "It is our job to participate in a conspiracy of hope…. First, we must be committed to changing the environments where people are being asked to grow. We must recognize that real change can be quite uncomfortable and sometimes I worry we will content ourselves with superficial change."[2]

Table 31
Types of Advocacy: Strengths and Limitations

	Strengths	**Limitations**
Self-Advocacy (individual advocates for own needs and grievances)	• Conviction of the person to achieve a better life • Grounded in personal story or issue • Honours voice of individual	• Often limited impact on policy • May be impeded by limited knowledge of systems

Individual Advocacy (person or peer works with and represents the interests of another person)	• Knowledge of advocate • Voluntary relationship • Ideas generated through relationship and conversation • Can link to broader issues • Resources of ILRC can be used to assist	• Often limited impact on policy • Issue may get distorted if advocate is not independent of services
Agency Advocacy (agencies advocate for the person)	• Resources of agency • Understanding of systems and community infrastructures • Agency bureaucracy	• Conflict of interest when agency is providing other services
Collective Advocacy (group promotes and changes conditions)	• Collective action possible • Many options (e.g. lobbying, legal action, etc.)	• Difficult to know when to escalate • Does not necessarily meet the needs of each individual

The Canadian Independent Living movement decided early on that it would stress individual advocacy (and self-advocacy), not collective advocacy. In part, this decision was made because CCD and other national groups were already doing the collective advocacy. Taking this approach meant that advocacy within Independent Living in Canada would play a different role than it had in the United States, where Independent Living Resource Centres do collective advocacy. For Allan Simpson and other leaders, the IL approach in Canada meant a focus on *both* individual advocacy and self-advocacy. Simpson had said at the time, "A light dawned in my mind that here was a chance to work at the other end of the spectrum. Rather than limiting ourselves to broad, political-social change, we consumers could go back to our grassroots and work with individual growth and development. We could help people to represent themselves rather than always having groups represent them."

There are subtle as well as distinctive differences between self-advocacy and individual advocacy. Although both honour the self-determined decisions of the person, self-advocacy means that the person is advocating on behalf of him or herself. Individual advocacy means that another person acts on behalf of the person with the grievance. In the Independent Living movement, self-advocacy and individual advocacy are strongly intertwined. Advocacy coordinators say they promote self-advocacy, but if the person wants individual advocacy to assist their cause, centres provide such support. As Allan Simpson suggested, the key linkage between the two types of advocacy is self-representation.

Learning to represent yourself has become an important theme within Independent Living Resource Centres. The core program of individual advocacy is strongly linked to citizenship and the idea of self-representation. Within a citizenship model, individual citizens have rights and freedoms. These include the right to speak up about issues and the right to be free of discrimination. Donna Herrington, former executive director of the Niagara Centre for Independent Living, has put it most succinctly: "Having individual advocacy truly enables us to have full citizenship. Through education and support, power is put back in our hands, which allows us to take risks. Eventually, this ripples down into the community resulting in social change."

Despite the decision by the movement early on to focus on self- and individual advocacy, many leaders emphasize the importance of collective advocacy in the struggle for change. David Shannon, a CAILC board member and lawyer, says, "Collective advocacy is very important. The individual is lost without this because it provides the basis for broad awareness, and we all learn through these advocacy activities." Shannon explains that collective advocacy gives hope and provides advice for individuals and centres. He notes that, "Collective work is key in showing role models and leadership structure."

Disability leaders celebrate Supreme Court victory of Council of Canadians with Disabilities (CCD) vs. ViaRail

In the last few years, for example, CAILC itself had intervener status in the Via Rail Case,[3] a prime example where collective advocacy was inspiring for centres and consumers. David Shannon, who acted as one of the lawyers who prepared the CAILC submission to the Supreme Court, says the Via Rail victory was significant because "it promoted greater participation in society."

The Process of Self-Advocacy and Individual Advocacy

Similar to other centres, the Thunder Bay Independent Living Resource Centre has evolved to the point where it has identified three steps in the advocacy process. The *first step* involves the advocacy coordinator helping the individual identify his/her needs, including clarifying the issue that may require advocacy. An individual consumer may be frustrated with their housing situation, but may benefit from questions designed to sort out what the essential housing issue is that needs addressing. Is it problems with the landlord? Is it related to the fact that housing and support are too enmeshed, so that it is impossible to move without losing support?

The *second step* involves the advocacy coordinator explaining what resources and supports are available to assist with solutions, and how to explore some of these resources. This might involve making the consumer aware of resources both within and without the centre. This step might also involve identifying people and places that would support the person's vision to resolve the situation. According to some advocacy coordinators, it can also involve an explanation of the differences and connections between self-advocacy and individual advocacy.

The *third step* focuses on supporting the person to access what they may require to resolve the issue, including information, training, or other people who can help empower the person. This might involve some detailed planning and the development of an advocacy action plan. If it is a short-term advocacy issue, a few immediate steps might be developed. If it is a longer-term advocacy issue, the person may be encouraged to gather more information, take a workshop on strategies to address this issue, or be linked with a mentor who might assist with problem solving.

Paula Saunders, advocacy coordinator from the Waterloo Centre, stresses that the advocacy process is very individualized, depending on the person's needs. Saunders describes what typically happens: "After being contacted by the individual, a meeting is set up. After discussion on what they are working towards, different methods would be used. It could mean gathering information for them to do the work themselves. Or it could mean further meetings to work through the issue and the best approach to take. On occasion, it has meant going with them to a meeting to be a support for them. I have also matched people with others who have either been through the same issue or are interested in working with someone to achieve their goals."

Mike Hambly, advocacy coordinator with the Calgary Centre, agrees and adds that, "Most people who seek support come in with more than one issue." Hambly points out that people's issues can be quite varied and complex, and "that often requires people to prioritize what they feel is most important." In terms of the process, Hambly stresses that it is important to take direction from the person. "Although we make suggestions," says Hambly, "it is the individual's choice whether they take them or not." Furthermore, he notes, "A person defines their own independence and they define their own successes."

The Thunder Bay Centre has a motto, designed by Linda Cairns and Pat Seed, on the importance of information, confidence, control, and support in the process of gaining independence:

Information plus knowledge equals Confidence
Confidence plus determination equals Control
Control plus support equals Independence.

This insight from Thunder Bay is supported by research on the process of how people increase their sense of control and empowerment.[4] Opportunities to learn are important in the process, as are people who can provide support and mentoring, as well as the right resources. The other piece in the empowerment puzzle is the importance of internal motivation, what Thunder Bay calls determination. In order for external supports and resources to be effective, people must want to change.

In a similar way, advocacy coordinators are always trying to provide effective process, but individuals themselves must strongly desire to resolve the issue that they are facing. In many cases, people may know it will take years for them to resolve their issue. People who stay with an issue for an extended period show great perseverance.

Individual Advocacy and Its Role Within Independent Living Resource Centres

Leaders of the Independent Living movement understand that advocacy is needed for many reasons. First and foremost, too many people with disabilities are denied their rights. The Saskatchewan Voice of People with Disabilities made this clear in their 2000 publication *Self-Help Guide to Independent Living*. This resource states:

YOU have the right to…

- Make decisions;
- Dignity and respect;
- Be included in the community;
- Have a place to live;
- Meaningful employment;
- Justice;
- Equality.

The goal of individual advocacy, as defined by CAILC, is to promote the development of self-advocacy skills so that people can reach their own solutions to their problems based on information and skills they have acquired. Furthermore, CAILC notes that:

> The provision of individual assistance is sometimes necessary in helping persons with disabilities to remove barriers to independence and obtain what is rightly theirs from systems or institutions with which they interact. Support and learning to manage, coordinate, and negotiate with a wide range of community resources can be crucial in making independent living a reality.[5]

As a result, most centres emphasize IL empowerment skills enhancement as a way for consumers to become more effective in their own lives as self-advocates. Skill enhancement is offered through a variety of formats, including workshops, mentoring opportunities, and other educational options in the wider community. Table 32 outlines the CAILC definition of skills development and the main principles that guide initiatives in this area.

Table 32
Independent Living Skills Development:
Canadian Association of Independent Living Centres

Communicating, negotiating, problem solving, and personal management are all important aspects of daily life. The IL Skills Development as a core program 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 assist consumers to enhance their creativity and problem-solving skills.
- To assist individuals in reaching their Independent Living goals by taking a proactive, solutions-based approach to conflict and problem solving.
- To provide tools, support, and resources to create lasting positive change in both individuals and the community.

Individual advocacy requires that centres build capacity “one person at a time.” In many ways, it is easier to build the necessary relationships in order to change the thinking or attitude of one other person, but much slower to change a culture.

As we shall see, IL skills development gradually builds a large group of empowered, skilful individuals who can self-advocate and co-operate together for change. Table 33 outlines examples of problem solving that can be part of skill enhancement to build self-advocacy capacities.

The decision of Canadian IL leaders to choose individual advocacy/self-advocacy as one of its core programs has grounded the Independent Living Resource Centres in the daily life issues of citizens with disabilities. Because centres are places where people can seek individual advocacy support, staff hear many stories that can break your heart; stories of people living lives of homelessness, poverty, and acute loneliness are not uncommon. While these stories keep staff focused on people's real issues, they also create the basis for community development. Through individual advocacy and training people to be self-advocates, centres learn which issues are important to consumers and where more focus is needed in their community work. Many centres have become engaged in employment or housing issues, for example, because it became clear over time that many consumers were concerned about these issues.

Table 33
Problem Solving and Skill Enhancement

Problem solving is the heart of effective individual advocacy. The individual, as well as people supporting the person, must be able to effectively analyze the problem, develop strategies for overcoming the problem, and link with resources (both technical and people-oriented) that can assist in the resolution of the issue. The experience at centres is that many consumers need skill enhancement in order to be effective in problem solving.

Problem solving through individual advocacy is sometimes quite direct and rapid, and becomes part of the training toward self-advocacy. At one centre, a staff person described how receiving a phone call from someone with a problem might involve the staff person phoning an agency to resolve the issue over the phone on behalf of the person. This kind of individual advocacy may sometimes be needed. However, the skill enhancement approach to individual advocacy emphasizes that consumers themselves develop the skill and confidence to make their own phone call. Skill enhancement approaches, then, are an important part of problem solving and self-advocacy.

Centres stress that skill enhancement must never be used as “victim planning.” In such an approach, solutions are often seen as being out of reach of the person unless they improve their skills. This idea that consumers *must* develop a certain level of skill before they can be successful can be very discriminatory to those people who are unable to meet the expectations of others. Rather, centres offer skill enhancement as *one way* for the consumer to deepen their understanding and strategic approaches to problem solving. The reality is that skill enhancement is a limited strategy for some consumers. Furthermore, as one leader said, “the problems facing people with disabilities simply don’t evaporate with effective advocacy,” and many issues require multi-layered approaches to change.

Individual advocacy has sometimes been a tricky road for Independent Living Resource Centres. In some communities, centres had to defend the idea of individual advocacy vigorously. Carole Sénéchal, board chair of the Trois-Pistoles Centre for 15 years, describes how challenging it was to educate other groups doing collective advocacy. Sénéchal recalls one particular meeting with advocacy organizations, where there was intense discussion about Independent Living principles. “People were saying that what the ILRC wanted to do was already being done by existing advocacy organizations, so why create another organization duplicating the work.” Trois-Pistoles and other centres find it necessary to put a great deal of effort into building the case for individual advocacy. Sénéchal notes that, “It took a lot of work to give people a better grasp of this, and I would say that this process remains incomplete. Indeed, many people don’t really differentiate between the roles played by an IL centre and a collective advocacy organization because they see two organizations reaching the same people with disabilities, so for them it’s the same.”

Pierre Majeau, a leader in Quebec from the Montreal Centre, summarizes why individual and self-advocacy are so important to the Independent Living movement: “I think that one of the primary characteristics of an ILC is the provision of individualized support to people in their development, helping everyone go as far as possible along their own path, with the understanding that people have the right to make mistakes.” The centrality of individualized support is a key aspect of centre work for Majeau. He notes that ILRCs are developing alternatives, almost becoming a laboratory for testing new ways of meeting people's individual needs. For example, some centres have been applying IL principles to older adults. He believes that the idea is to build on these alternatives, and what may originally have been an experiment may eventually become a standard or common way of meeting people's needs.

The point of individual advocacy for Pierre Majeau is to intervene and provide support on an individual level and be able to test out certain ways of meeting needs that are currently unmet, poorly met, or met in a way inconsistent with the IL philosophy. Majeau stresses that, "Individual support *and* individual advocacy must continue to make up the ILC's identity." In reflecting on Quebec, Majeau notes that many organizations are involved in group advocacy. Despite that, he notes, "The resource mechanisms for supporting individuals to resolve their issues are difficult, complex, inaccessible, or unsuitable and do not factor in people's specific needs. Therefore, I see individual support and individual advocacy as a possible future area of development for ILRCs, depending, of course, on their regional context and circumstances, but I think that there is a significant need around which expertise could be developed." Table 34 lists some tips from advocacy coordinators at ILRCs. These insights show how well developed some individual and self-advocacy has become.

Table 34
Tips From Advocacy Coordinators

Advocacy coordinators at centres have identified 12 tips they share with the people they support to advocate for themselves:

1. Clarify your issue—figure out what it is you really want and need;
2. Gather facts and information—become knowledgeable;
3. Study systems, procedures, and appeal mechanisms—do your research fully;
4. Plan carefully—always revisit your plan because plans change;
5. Connect with people and places that can help—build relationships;
6. Document everything—keep good records;

7. Stay positive—do not get discouraged;
8. Tell people about your issue and why it is important—tell your story;
9. Write letters and emails—communicate clearly;
10. Follow up letters with phone calls and meetings—be persistent;
11. Contact people with power—seek out “powerful strangers”;
12. Constantly assess and reflect—evaluate progress regularly.

Cassandra Phillips, former chair of CAILC from Saskatchewan, has written that, “The relationship between self-advocacy and independent living is synergistic.” Phillips notes that, “From an ideological perspective, self-advocacy means freedom and responsibility, risk and reward, choice and control: principles fundamental to IL.” She adds that, “Self-advocacy and individual advocacy are contingent on the choices available to us, and the power that we have to follow through on the decisions that we make.”[6]

Both Majeau and Phillips emphasize that self-advocacy and individual advocacy show people “what is possible.” In this way, advocacy is complementary to another core program: research and community development. Self-advocacy and individual advocacy often identify issues and concerns that can then be used as a basis for further research or community development. It is also true that without change at the individual level, lives would not improve. For example, convincing one landlord to make an accessible apartment is faster than getting a city to mandate that more units that are accessible be made available. However, the point is that both kinds of advocacy are needed. Self-advocacy and individual advocacy should never be “one off” advocacy but should always remain open to the path to a systemic solution.

Centres report that there are a growing number of resources available for staff and volunteers who are supporting people in their self-advocacy. One of the best was created by the North Saskatchewan Independent Living Centre. Entitled *Change Is Inevitable, But Growth Is Optional*, this self-advocacy manual is filled with ideas and strategies for advocacy. Designed to be used as part of a facilitated course on self-advocacy, the manual emphasizes that self-advocacy requires knowledge, courage, action, and risk. Practical questions and exercises guide the reader through the advocacy process, including defining the issue, gathering information on the issue, and identifying the supports you require to resolve the issue. The manual then goes on to explore several key communication approaches that advocates need, as well as effective advocacy strategies with various levels of government.[7]

Advocacy and Innovation: Starting With Me, Moving to Us

All centres have experience in supporting individuals who are advocating for change in their local community. Usually, a person's request for change is fuelled by their passion for a particular issue. Such self- and individual advocacy can sometimes make a huge contribution to local innovation. We share two consumer stories that began with individual frustrations and concern for change. In both cases, individual advocacy led to collaboration with others to create a local innovation.

The first story of advocacy and innovation is about Casey Morrison from Collingwood, Ontario. He spearheaded a movement to improve accessible transportation in the Collingwood area. Morrison's story shows how advocacy often requires persistence, knowledge, and strategy. It also shows how other people are vital to advocacy, whether they be trusted family and friends or influential community members, such as politicians.

Casey Morrison uses an electronic device to communicate verbally. His inability to use the telephone is no barrier when it comes to making people hear what changes are needed in the community. Morrison has a way of helping people listen to what he has to say. He is a great example of people taking control of their own life through participation and advocacy.

Table 35
Advocacy for Change: Casey Morrison's story

Casey Morrison is a young man who lives in Collingwood, Ontario. He has been connected for some time with Breaking Down Barriers, the local Independent Living

Resource Centre. Like many advocacy stories, Morrison's story begins with a person who sees injustice. As a leader in his community, he had been frustrated for years because Collingwood did not have any accessible public transportation.

Casey Morrison

Casey Morrison's vision was quite simple. To start with, he wanted the city to fund an accessible taxi for himself and for others. Morrison recalls giving a speech at the Jubilee Committee Meeting in September 2005 about the need for an accessible taxi. "The committee agreed," he says. "They told me to write a letter to the Ace Cabs' owner (Paul Spencley) to ask him to come to the next meeting in October." In October, Spencley came and they talked about the possibility of an accessible cab with him. He wanted to get it, but he needed $15,000 to make one of his vehicles into a wheelchair accessible cab. The Committee would not agree to fundraise. Morrison recalls how he felt. "I started to get frustrated with them after the second and third meeting. I made a list of businesses that might want to help us to get money. I also went to all of the banks in town. They also wanted to help, but they needed to get a letter from the committee!"

At this point, Morrison told his mother that "the town didn't want to get it!" Morrison says his mother "encouraged me to think of different steps. She said that the town should do this, and if they didn't, then I could go to the public." Morrison then started his advocacy with town councillors Rick Lloyd and Norm Sandberg. He wrote letters and delivered them. Morrison found a positive response. "They emailed me back, and said they would help and they would get others to work on it too. I also talked to Bill Plewes (at Town Hall), and he set up a meeting with the town's Accessibility Committee for me to go and talk about the taxi."

A few weeks later, Morrison and his friends convinced the local cable TV station to do a story on transportation. Casey Morrison, along with Councillor Rick Lloyd and taxi owner Paul Spencley were interviewed. Morrison recalls that this built momentum. "It was good on the TV," he says, "and a lot of people saw it and wanted to help me. It made a lot of people in Collingwood realize that there is NO transportation available if you have a wheelchair or scooter except for the Red Cross that only goes 8 a.m. to 5 p.m., Monday through Friday, *if* you book one week ahead." The local newspaper also did a story and Councillor Lloyd said that he was going to present to council the need to supply two vehicles for taxis, and the money would come from the gas tax rebate.

Shortly after, three councillors put together a plan to take to the town's Accessibility Committee. The first time the committee reviewed the proposal, they turned it down. A month later, the committee met with Casey Morrison and Kathy Bloomfield from Breaking Down Barriers. They explained why a wheelchair accessible taxi was needed *now* and that the city should look at making buses accessible in the future. This time the committee voted in favour of the proposal. Two weeks later, Councillor Rick Lloyd asked Morrison to come to the council meeting to help explain the taxi. Morrison says, "They were really interested." Morrison continued his advocacy and attended several budget meetings to ensure that the proposal was built into the new budget. On May 23, 2006, Collingwood Council passed the town budget and the taxi and transportation plan was passed!

At the 2006 Annual General Meeting of the Collingwood Centre, a city councillor announced that Collingwood had agreed to make their buses accessible and to fund an accessible taxi. Casey Morrison was presented with the Barb Meacher Memorial Award for his advocacy. There was excitement in the air as people cheered Casey Morrison in appreciation for his hard work and persistent advocacy. Although Morrison's efforts began as a self-advocacy journey, the process, in fact, mobilized many folks in Collingwood around transportation and inclusion.

Our second story of advocacy and innovation involves Peter Hulme, a young man who lives in Waterloo, Ontario. Hulme believes he had the right to receive support in his own home in the community. As he fought for this support, Hulme realized that he would need to create the alternative for himself. So, he collaborated with two peers, found support through an Independent Living Resource Centre, and eventually convinced government to be a player in a new community-based, innovative project. This story reiterates the importance of perseverance, and the ways in which self-advocacy often tends to weave into collective advocacy.

Table 36
Advocacy for Change: Innovation and Leadership in Waterloo Region

When Peter Hulme graduated from high school in 1988, only one university in Canada provided support to students with significant physical disabilities. Fortunately for Hulme, one of his teachers, Pam Byrant, was working hard behind the scenes to create an individualized support project at the University of Waterloo in collaboration with the Independent Living Centre of Waterloo Region. Peter Hulme and four other students scheduled to attend the University of Waterloo that fall had a nerve-racking summer, as the funding for the project from the Ontario government was not approved until mid-August.

Peter Hulme

Rose Padacz became the project coordinator and worked closely with the five students to create a flexible initiative that responded to the needs of all the students. In reflecting on the innovative approach they took, Padacz says that integration was a key part of the initiative. Staff encouraged the students with disabilities to call upon peers and volunteers to participate with them as attendants at various activities on campus and in the community. Attendants played a key role in enabling the students to experience a full life on campus and to have access to classes and libraries in the same way that other students did. All five students had very successful university careers.

While at the University of Waterloo, Peter Hulme met Dan Lajoie and Jeff Rasmussen, two other students with disabilities in the ILC University Project. When Rasmussen was nearing graduation, he realized that his future was very uncertain unless he could address the lack of accessible, affordable housing in the community. Hulme was also deeply concerned. A year earlier, he had graduated in psychology, but decided to stay in university with appropriate assistance rather than return to his parents' home. What happened next was an experience that Dan Lajoie says "fundamentally changed my life."

Together, these three friends began to advocate and push for the supportive housing they knew they had a right to in the community. Along with Lynn Smith, the university project supervisor, they applied to the government for funding to start a new supportive housing project as part of the Independent

Living Centre of Waterloo Region. After months of lobbying, they finally found a sympathetic civil servant, who helped make the funding available through a provincial government ministry. They also needed to find a property owner who would allow the necessary renovations to accommodate their accessibility needs. They wrote dozens of letters, and finally found a supportive landlord. They also had to raise funds for automatic door openers. "When we started the project we were severely underfunded," notes Lajoie, and for some time attendants worked above and beyond their required duties. Today, the Albert Street project is still running, with ten consumers living in ten apartments in a large complex. Though the three advocates have moved on, Lajoie says, "It was a pretty unique effort…. Starting the project was an introduction to the world of politics and bureaucracy and to the role of being an advocate. " These three very successful young men proved that innovation is possible with the right type of advocacy!

Dan Lajoie

Contradictions of Individual Advocacy

Individual advocacy does create some contradictions and dilemmas for centres. Three of these will be briefly explored.

First, it is recognized that both individual advocacy *and* self-advocacy are cornerstones of the Independent Living movement. But, as Allan Simpson wrote in 1993, "It is a constant challenge for staff, board members, or volunteers to determine when to advocate for the person and when the person should advocate for themselves." Leaders realize that there is sometimes tension between individual advocacy and self-advocacy. Allan Simpson analyzed this tension as a reflection of a movement trying to reach out to a broad range of people with disabilities. He explained that, "As we struggle with people who have multiple disabilities, less articulation, and less education than many of the original members of the consumer movement, it is a constant search for how they can represent themselves." Centres report that this is difficult work, but the wisdom of Allan Simpson rings true today. He understood that this search for each person's voice and self-determination was winnable. He stressed that "…every person, no matter what level of intellectual skill, experience, or training can express in one way or another their true feelings, their own true needs. It is our job in the Independent Living movement to bring out the true feelings, the true wishes of that individual, rather than to dominate them with our views."

Second, even though advocacy efforts may, in fact, resolve an issue for a consumer, this usually does not lead to broader change for all consumers. This contradiction means that centres must decide whether they should move this individual concern to broader-level community development and collective advocacy or not. Some centres seem to move seamlessly to community development when they have a few similar situations that require attention. For example, staff might reach out to literacy groups in their community after realizing that several of their members are having difficulty accessing appropriate literacy support. Other centres encourage members to form their own advocacy group once they have identified several consumers who are working on a similar issue.

Third, advocacy requests tend to be quite specific and focused. The person seeking support is usually looking for a concrete resolution to a problem. How do I deal with an unreasonable landlord? How do I stop what I think is discrimination at my workplace? Centre staff must decide whether the advocacy question requires a very specific response or a process that broadens the individual's perspective of the issue. A specific response would see the staff person help the individual resolve that specific issue. Responding with a broader process might see the advocacy coordinator propose that the person engage in a planning process that looks at ways to build a good life in the community. The South Saskatchewan Independent Living Centre in Regina, for example, utilizes a person-centred planning process that is designed to assist people in making decisions about their own future. Some centres have noted they do not have the resources to facilitate a lifestyle planning process with people, even though that is what is often required.

Paula Saunders, advocacy coordinator from the Waterloo Region Independent Living Centre, shares a story that illustrates how the advocacy process may start with personal planning and then move back to advocacy. "A gentleman in his early forties realized that he needed to make plans for his future as his parents were

Paula Saunders (seated) with Dan Lajoie, Andrena Lockley, and Lorene Collingwood of the IL Centre Waterloo Region

aging and he would not be able to count on them for his care and his life," she explains.

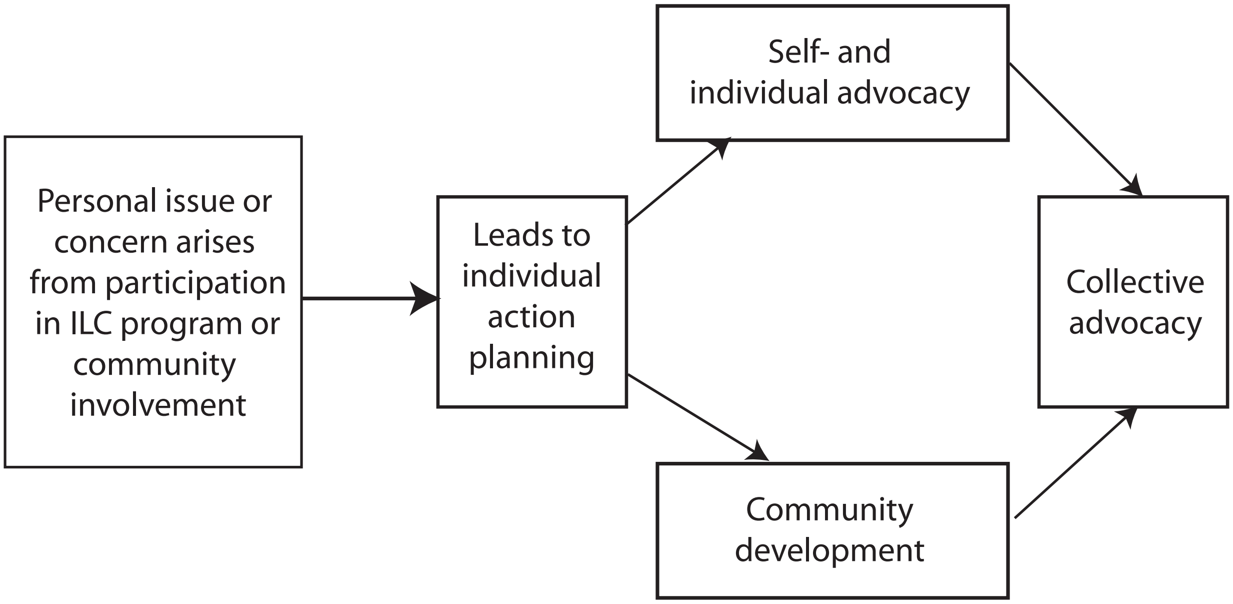
Numerous planning meetings were held to determine what he was looking for, what was available in the community, and what would fit his needs and wants. Saunders adds, "After determining what he wanted, he sent out applications and went through many steps to get into a supportive housing unit." Although this took time and advocacy, Saunders notes that "there have been many changes in this man's life over the years and with each of these changes, we have worked together to make the changes with him."

Summary and Reflection

Some leaders have described Independent Living as an *enabling process* that builds confidence, self-esteem, and self-empowerment.[8] When individual advocacy is done well, it enables and empowers. Sandra Carpenter from the Centre for Independent Living Toronto describes part of this process. "Staff in ILRCs concern themselves with working with people to help them find the most appropriate solution—the one that fits the individual's idea of what they want, not always the most typical or common solution. This is what makes an Independent Living Resource Centre an alternative among many other programs and services targeted toward people with disabilities."

In many ways, individual advocacy is the least likely of the Independent Living programs to stand alone. The need for advocacy can emerge from multiple sources and is often connected with other resources. Individual advocacy often emerges out of a process where someone is stuck, perhaps having hassles with bureaucracy. At some point, the frustration and resistance to change might be such that advocacy is the next logical step. Furthermore, advocacy may emerge out of individualized support arrangements. A staff person may be working with someone who wants to start a new career or who wants to get a driver's license. This individualized planning process may become advocacy if the formal institutions or bureaucracies that this person is attempting to be part of are resistant to inclusion of a person with a disability. As we have seen, advocacy situations generally access information and networking, and may often lead to research or community development because an individual advocacy issue keeps recurring among members. Table 37 shows a schema of possible advocacy relationships.

Table 37
Schema of Possible Advocacy Relationships



Staff or volunteers who facilitate individual advocacy are most effective when they are free of conflict of interest. Most centres are well situated to facilitate and support individual advocacy because they do not provide extensive hard services, such as housing. A few centres have struggled with conflict of interest because they are providing a range of direct services. Like planners, advocacy coordinators do their best work when they consider the wider community and not just the services in their own domain. When advocacy coordinators cannot be fully independent, they need at least to be aware of their own conflict of interest and its effects on their work. Table 38 highlights the evolution, benefits, and challenges of individual advocacy within Independent Living Resource Centres.

Table 38
Individual Advocacy Within Independent Living Centres: Evolution, Benefits, and Challenges

1. Individual advocacy has been a principle and core function of Independent Living Centres since their inception in Canada. Although named "individual advocacy," the goal is to support people to gain the confidence and skills to enhance their self-advocacy.
2. Consumers and centres report that individual advocacy is a very positive resource that assists people in problem-solving personal and social issues. IL skills enhancement programs are often available at centres for consumers who want to deepen their self-advocacy skills.
3. It has been shown that individual advocacy is strongly linked to individualized planning and support. The need for advocacy often emerges as people seek to change their lives.
4. In many cases, individual advocacy merges with collective advocacy and community development. Centres have learned that some individual issues benefit from more systemic approaches.
5. Consumers and centres report that advocacy has many benefits, including increasing self-confidence, building knowledge and awareness, and expanding the sense of empowerment.
6. Advocacy coordinators and others who facilitate individual advocacy face some contradictions that influence how decisions are made. It can be challenging to decide whether to support individual advocacy or self-advocacy, whether an individual issue can move to community development or collective advocacy, or whether the resolution of an individual's issue is specific to that issue or better resolved with a broader planning process with the person.
7. Advocacy is best facilitated when the people doing the advocacy are free from conflict of interest. Most centres are well situated to facilitate and support individual advocacy because they do not provide many hard services in their community.

Finally, it should be remembered that individual advocacy is grounded in citizenship and the belief that people with disabilities can and should participate fully in all aspects of community life. We know that this vision is still far from reality for many citizens with disabilities. Advocacy, in all its forms, is needed to deepen the possibility that citizenship conditions and opportunities can continue to expand for all people.

> *The advocate as leader: "The wise leader knows about pairs of opposites and their interactions. The leader knows how to be creative. In order to lead, the leader learns how to follow…it is the interaction that is creative.*
>
> —John Heider, *The Tao of Leadership*

Endnotes

1 Aldred Neufeldt, "Disability in Canada: An Historical Perspective," in *In Pursuit of Equal Participation,* eds. Henry Enns and Aldred Neufeldt, (Toronto: Captus Press, 2003).

2 Pat Deegan, "Recovery in Community Mental Health," presentation to Canadian Mental Health Association, Waterloo Region, October 2003. For further information, see [www.patdeegan.com].

3 The Via Rail Case involved the railway buying non-accessible rail cars because they were cheaper, thus making access for people with disabilities a low priority. This decision was challenged in court and Via lost.

4 See research on personal empowerment, outlined in detail in Chapter 5.

5 CAILC, *A Guide to Independent Living Centres* (Ottawa, ON: Canadian Association of Independent Living Centres, 1990).

6 Cassandra Phillips, "Steering Our Own Ship: The Growth of Individual Advocacy Within the Canadian Association of Independent Living Centres," in *Making Equality: History of Advocacy and Persons with Disabilities in Canada,* eds. Deborah Stienstra and Aileen Wight-Felske (Toronto: Captus Press, 2003): 197–219.

7 North Saskatchewan Independent Living Centre, *Change Is Inevitable, But Growth Is Optional* (Saskatoon, SK: North Saskatchewan Independent Living Centre, 2000).

8 Cassandra Phillips.

Chapter 9

Research Capacity and Policy Development: Role and Influence of Independent Living

Research and policy are both vital dimensions of social movements. Without a strong research base, social movements can easily slide into ideology that lacks substance and credibility. For Independent Living as a social movement, research and policy serve as a bridge between its members and the wider society. Research can describe and explain how people with disabilities experience Independent Living. Policy that reflects Independent Living values and principles gives credibility and sustainability to the concepts. The Canadian Association of Independent Living Centres (CAILC) has long been interested in the role that research and policy plays in both advancing the movement and in influencing government frameworks toward citizens with disabilities.

Policy is important because it sets guidelines and principles for action. Few social movements ignore social policies of governments because they know that policy affects the kind of initiatives that receive funding support. Government social policy is influenced by many factors, including the research, experiences, and advocacy of social movements. Governments are well versed in the fact that social movements give "voice" to the real issues that people are facing. Government policy related to Independent Living in Canada has been incremental at best, but there is no doubt that it has been significantly influenced by the disability movement. As Henry Enns and Aldred Neufeldt argue in their book, *In Pursuit of Equal Participation*, historically, there is a kind of symmetry of roles between government policy and the efforts of the disability movement.

Some leaders have identified barriers that the Independent Living movement faces in influencing research and policy. Sandra Carpenter from the Centre for Independent Living Toronto points out that there are multiple definitions of disability and that various disability groups that are working for disability rights do not always agree.[1] Carpenter says these contradictions are challenging for policy makers, who need to figure out how to frame disability support policy. She notes, however, that the contribution of the Independent Living movement helps to ground many common elements that people with various disabilities can share. These elements include "a framework which recognizes individual choice and control as central principles." Carpenter also stresses that all disability groups are seeking equality and the right to be treated as persons. Even though Carpenter wrote this in 1993, it still rings true today. Most government jurisdictions still experience confusion about what is common among people with disabilities and how policy could reflect this insight.

Social movements have become increasingly sophisticated with building research capacity and influencing policy development. In the early years, the Independent Living movement borrowed heavily from the American experience and used that research to shape what Independent Living might look like in Canada. When the national association was formed in 1986, Canadian research became more important, since the Canadian Association was now representing numerous centres in deliberations with the federal government. Although some IL research was completed in the 1980s, Independent Living research projects became more prevalent in the 1990s. In 2003, the national association appointed a research consultant to its staff, increasing the link between movement research and government policy. This was one indication of the growing importance of research to the movement.

Research fuels both policy and practice. From its earliest days, the Independent Living movement in Canada has used research as a tool on which to build social change. There are four interrelated ways that research is utilized. Research is used as *knowledge production*, usually involving the national association or local centres working in partnership with academic researchers. Although partnerships with university researchers have sometimes been problematic, CAILC has built very positive partnerships with a few academics. Research is also used for *knowledge dissemination,* which often involves sharing lessons learned. Thirdly, research is used for *utilization,* which includes using research to change an Independent Living approach. Finally, research is used for *community mobilization*, such as needs assessments, community forums, or action research designed to animate a new approach with community members. We shall now explore each of these approaches to research.

National Association Builds Research Capacity

Focus on Knowledge Production

In 1985 the Centre for Research and Education in Human Services (now called the Centre for Community Based Research) in Kitchener was in its third year of operation. The Secretary of State approached founding director John Lord and asked if he would lead a study of the first three Independent Living Resource Centres in Canada. Leaders at centres in Kitchener, Winnipeg, and Calgary agreed that John Lord and his team should take on this study. Lord convinced the federal government and the centres that for this study to be effective, it would need the full participation of the centres. A national steering committee was formed that included researchers and representatives from the centres and the federal government.

This first study on Independent Living in Canada was published by the Secretary of State in January 1987. Entitled *Toward Independence and Community: A Qualitative Study of Independent Living Centres in Canada*, this study highlighted themes and issues that were not well known at the time. Written by John Lord and Lynn Osborne-Way, this report included chapters on core programs and issues, such as consumer control and peer support. The research and insights in this report became a template for other centres that were getting off the ground in the 1980s and 1990s. This study also was seen by the federal government as a good investment in knowledge production that could be useful for knowledge dissemination.

In many ways, this community-based research study reflected principles of collaboration and consumer-driven approaches that made it a good fit with Independent Living. In reflecting on this research experience, John Lord says the "healthy tension" between researchers and consumer leaders created a powerful document. "As researchers," explains Lord, "we were somewhat detached and wanted to be sure we had evidence to back up all of our themes. The consumer leaders were passionate and knowledgeable and wanted Independent Living to shine. Each side had things to offer and the dialogue often illuminated a perspective that had meaning and depth."

Since the founding of the Canadian Association of Independent Living Centres in 1986, there have been many opportunities for collaborative research initiatives. The national association hired John Lord and the Centre for Community Based Research again in 1990. This time, Lord and his research team studied the nine Ontario centres and provided a framework for them to position themselves to have a collective province-wide impact on individuals and communities.

In 1996, the Social Science and Humanities Research Council called for research proposals that focused on the "integration of Canadians with disabilities." Peggy Hutchison, a professor at Brock University, developed a partnership with the national association and two other universities and was successful in receiving a grant to study the consumer and community outcomes of Independent Living Resource Centres. This project was to be the first of several partnerships between CAILC and university researchers. Building on the earlier studies by John Lord, these collaborations with university researchers stressed partnership, consumer control, and national steering committees. The idea that consumers could participate in research as leaders and directors, not just subjects, was taking hold. As we shall see, this shift toward consumer-directed research was to have a huge impact on the mindset of IL leaders and their confidence in working with researchers.

Long-time leaders in the Independent Living movement have certainly noticed that disability research and programs have expanded within universities. Cathy La France, former executive director at BC's Duncan Centre, notes, "There's been a number of disability studies programs emerge in academia, which is great to see…but I think it's new and it still has a ways to go before we see how much impact these programs will have in terms of research." Diane Dreidger from Winnipeg remembers that when Henry Enns founded the Canadian Centre for Disability Studies at the University of Manitoba, he intentionally used an "Independent Living lens" and a disability rights movement frame to guide the centre's work. Ryerson and York Universities in Toronto have both developed disability studies programs with an emphasis on research. As one leader notes, "This expansion of Independent Living concepts within traditional institutions of higher learning has certainly been encouraging."

The growing awareness of the importance of research within the Independent Living movement has not been without struggle. The reality is there are few researchers in Canada doing Independent Living research. The other reality is that it can be challenging for consumers to collaborate with academic researchers in a genuine partnership. Research, by its very nature, has a language and process that is often mystifying for the public. Historically, the research relationship is rooted in a power dynamic relationship, with the researcher having the power.

For these reasons, leaders in the Independent Living movement were always interested in research approaches that included people with disabilities in all aspects of the research process. They appreciated the idea of collaboration with academic researchers, but wanted a research approach that gave more control to consumers with disabilities. Fortunately, one research process and methodology addresses many of these concerns. Participatory research emerged as a legitimate research approach in the 1970s and was refined through the 1980s. John Lord and his colleagues at the Centre for Community Based Research utilized participatory action research (PAR) in several studies in the 1980s and 1990s.

However, it was not until the Centre for Independent Living Toronto published *Independent Living and Participation in Research*, by Gary Woodhill, in 1992 that CAILC had a framework they could use to guide research. Vic Willy, executive director of the Toronto Centre and long-time leader in the movement, was very involved in the process that created this document. He calls participatory research "a bright and beautiful thing." Willy noted that the Independent Living movement now had "a powerful tool for changing the processes by which we [as people with disabilities] are defined."[2] Table 39 highlights the main tenants of Participatory Research.

Table 39

Central Ideas in *Independent Living and Participation in Research, 1993*

Traditionally, research on disability has taken place within a medical model. People with disabilities have typically been objectified and have been treated as subjects, not participants in the research process. Researchers often assume that the focus of research should be on the deficits of people.

In recent years, it is becoming understood that deviance is not inherent to human nature, and that in fact most differences are socially constructed. Scientific methods are now coming under scrutiny as the disability movement and social constructivists challenge some of the assumptions of researcher control. A community model of Independent Living is seen as the most appropriate way to view Independent Living in our culture. With these new assumptions, what is the most meaningful type of research?

Participatory research is seen as the best fit with Independent Living. Proponents of participatory research are very critical of positivist social science; topics should not be chosen only by researchers; context and participation matter; and social knowledge should be owned by ordinary people. In this way, participatory research can be considered emancipatory, because people themselves are deciding on the research questions and the methods to be used to study the questions.

Although the process of participatory research may start with an experienced facilitator, control of the process rests with the participants involved. Action plans become the responsibility of the participants. In this way, participatory research promotes collective knowledge and analysis.

To be a good fit with Independent Living, research conducted at Independent Living Resource Centres should involve consumer-controlled research committees and recognize that tokenism is very common in research that claims to involve people with disabilities. A number of ideas are outlined for evaluating research proposals in light of Independent Living and participatory research.

In reflecting on participatory research, Fraser Valentine, former staff person with the national association, notes that this approach had always been of interest to the Independent Living movement. Valentine reflects, “I think that Gary Woodhill’s piece really consolidated and institutionalized that approach within the movement.” Paul Claude Bérubé, past chair of CAILC, says, “Participatory action research has been very important for CAILC and its network, because the principles are a good fit with Independent Living.”

Within two years of the publication of *Independent Living and Participation in Research,* CAILC produced a set of community research guidelines. Written by Kari Krogh and Lenka Petric in collaboration with the CAILC research committee, *Choice, Flexibility, and Control in Community Research* is a guidebook for centres. The guidebook shows how Independent Living research needs to reflect key principles. It also outlines different ways that centres can be involved in research (including endorsing, sponsoring, partnering, and directing). The guidebook also explains what meaningful consumer research participation looks like, and summarizes the roles and responsibilities of various players in the research process. Finally, it explores different research methods and lists the key rules of research, including ethics, informed consent, and confidentiality.

John Lord (right) presents award to Michelle Murdoch and Barry Galloway of Newfoundland

By 1996, the publication of this guidebook and subsequent research guidelines developed by the CAILC research committee demonstrated that the movement had found the right fit between Independent Living and research. To stimulate participatory action research, in 1999 CAILC created the John Lord Research Award for excellence in Independent Living research. The award has been given four times. In 2005, the award went to the St. John’s Centre for its research on Women and Adaptive Technology. Michelle Murdoch was the lead researcher on the project. The 2006 award was given to Tracy Odell for a study she completed with graduates of Bloorview Hospital, Home and School. Her research is a powerful, consumer-grounded reflection on life at Bloorview, a major institution in Ontario.

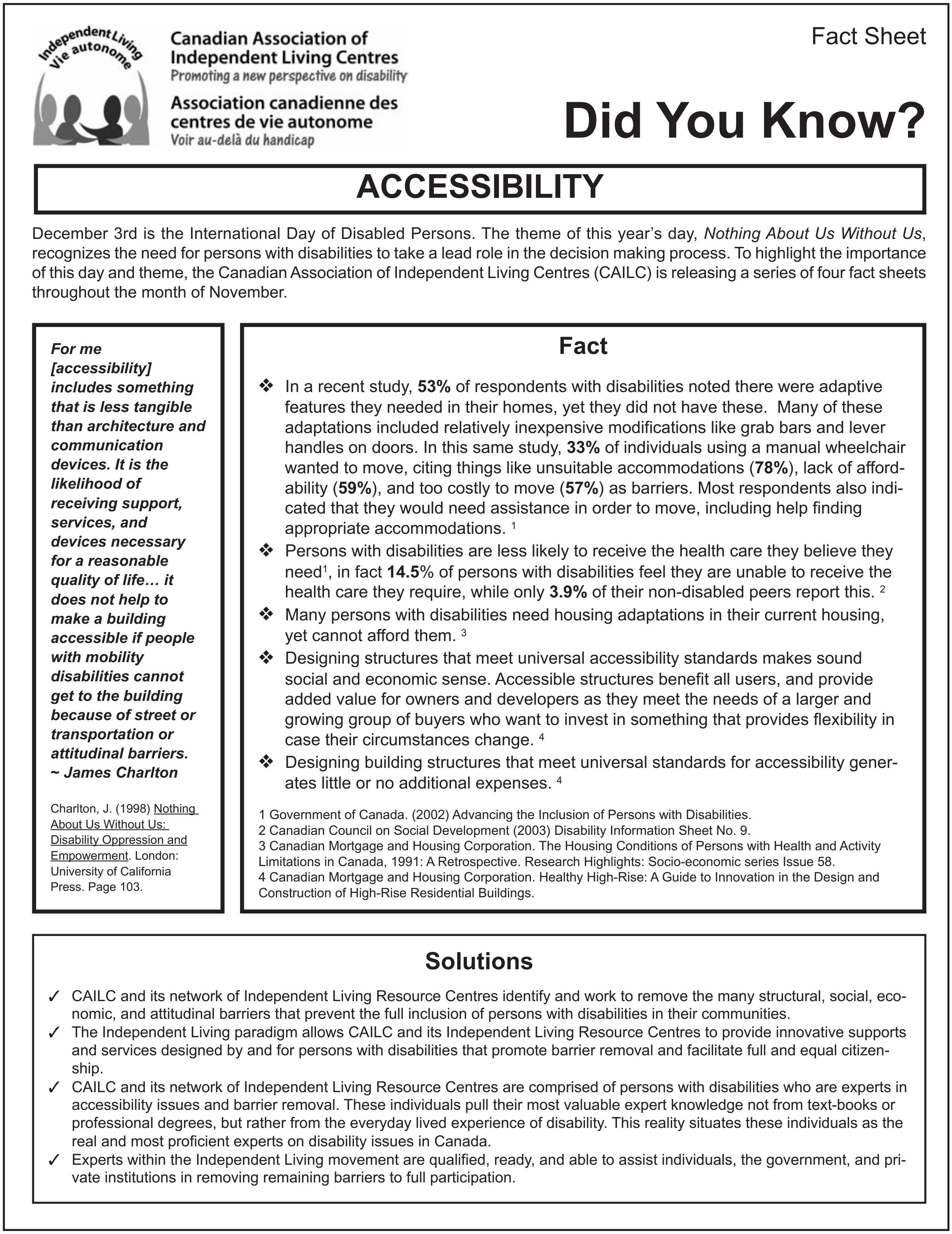
Despite these positive developments, the Independent Living movement has found it difficult to access funds for major research projects. Most research money in Canada goes to universities and community-based research centres. CAILC recently collaborated with other national organizations and a research centre to complete a study entitled *Enhancing the Research and Knowledge Mobilization Capacity of Disability Community Organizations*. The final report of this project makes several recommendations that could contribute to CAILC's research capacity in the future.

Focus on Knowledge Dissemination

Knowledge dissemination has always been an important strategy for social movements. In 2003, the Canadian Association of Independent Living Centres began to publish fact sheets on various topics that are of concern to citizens with disabilities. Created as a lead-up to United Nations Day for Persons with Disabilities, and released once a week for four weeks, the fact sheets became so popular that CAILC now publishes them annually as a key knowledge dissemination strategy.

A fact sheet is a one-page summary of a key disability issue, such as income support, housing, employment, accessibility, or rights. It highlights research findings and then proposes positive solutions based on knowledge about that issue. For example, the 2004 Housing and Homelessness fact sheet highlights that one in five Canadians with disabilities require some kind of adaptation to their housing. The summary also notes that 37.5 percent of people with disabilities in Toronto are living in poverty. The proposed solutions urge governments to fund non-profit housing adequately. It also encourages city planners, builders, and non-profit housing groups to draw on the expertise of Independent Living Resource Centres for support with housing design, accommodations, and housing options. Table 40 shows the fact sheet on accessibility created by CAILC in 2004.

Table 40
Accessibility Fact Sheet #4



Canadian Association of Independent Living Centres
Promoting a new perspective on disability
Association canadienne des centres de vie autonome
Voir au-delà du handicap

Fact Sheet

Did You Know?

ACCESSIBILITY

December 3rd is the International Day of Disabled Persons. The theme of this year's day, *Nothing About Us Without Us*, recognizes the need for persons with disabilities to take a lead role in the decision making process. To highlight the importance of this day and theme, the Canadian Association of Independent Living Centres (CAILC) is releasing a series of four fact sheets throughout the month of November.

> ***For me [accessibility] includes something that is less tangible than architecture and communication devices. It is the likelihood of receiving support, services, and devices necessary for a reasonable quality of life… it does not help to make a building accessible if people with mobility disabilities cannot get to the building because of street or transportation or attitudinal barriers.***
> ***~ James Charlton***
>
> Charlton, J. (1998) Nothing About Us Without Us: Disability Oppression and Empowerment. London: University of California Press. Page 103.

Fact

❖ In a recent study, **53%** of respondents with disabilities noted there were adaptive features they needed in their homes, yet they did not have these. Many of these adaptations included relatively inexpensive modifications like grab bars and lever handles on doors. In this same study, **33%** of individuals using a manual wheelchair wanted to move, citing things like unsuitable accommodations (**78%**), lack of affordability (**59%**), and too costly to move (**57%**) as barriers. Most respondents also indicated that they would need assistance in order to move, including help finding appropriate accommodations. [1]

❖ Persons with disabilities are less likely to receive the health care they believe they need[1], in fact **14.5**% of persons with disabilities feel they are unable to receive the health care they require, while only **3.9%** of their non-disabled peers report this. [2]

❖ Many persons with disabilities need housing adaptations in their current housing, yet cannot afford them. [3]

❖ Designing structures that meet universal accessibility standards makes sound social and economic sense. Accessible structures benefit all users, and provide added value for owners and developers as they meet the needs of a larger and growing group of buyers who want to invest in something that provides flexibility in case their circumstances change. [4]

❖ Designing building structures that meet universal standards for accessibility generates little or no additional expenses. [4]

1 Government of Canada. (2002) Advancing the Inclusion of Persons with Disabilities.
2 Canadian Council on Social Development (2003) Disability Information Sheet No. 9.
3 Canadian Mortgage and Housing Corporation. The Housing Conditions of Persons with Health and Activity Limitations in Canada, 1991: A Retrospective. Research Highlights: Socio-economic series Issue 58.
4 Canadian Mortgage and Housing Corporation. Healthy High-Rise: A Guide to Innovation in the Design and Construction of High-Rise Residential Buildings.

Solutions

✓ CAILC and its network of Independent Living Resource Centres identify and work to remove the many structural, social, economic, and attitudinal barriers that prevent the full inclusion of persons with disabilities in their communities.

✓ The Independent Living paradigm allows CAILC and its Independent Living Resource Centres to provide innovative supports and services designed by and for persons with disabilities that promote barrier removal and facilitate full and equal citizenship.

✓ CAILC and its network of Independent Living Resource Centres are comprised of persons with disabilities who are experts in accessibility issues and barrier removal. These individuals pull their most valuable expert knowledge not from text-books or professional degrees, but rather from the everyday lived experience of disability. This reality situates these individuals as the real and most proficient experts on disability issues in Canada.

✓ Experts within the Independent Living movement are qualified, ready, and able to assist individuals, the government, and private institutions in removing remaining barriers to full participation.

The CAILC fact sheets are an excellent example of knowledge dissemination in action. While much of this information may be known in the disability movement, people in mainstream organizations often lack such knowledge. The fact sheets can put information people need at their fingertips. With social inclusion as a goal, the Independent Living movement is constantly linking with other sectors of society. As we shall see with our analysis of national initiatives, the right kind of knowledge dissemination is crucial to the process of building alliances with non-disability organizations.

Centres also report that they have found the fact sheets invaluable. Several centres have used them with funding proposals, as part of their annual meetings, and as tools for educating politicians, policy makers, and corporations. The reach of this information is also demonstrated by the fact that some members of parliament have used them with their constituents. Research and knowledge dissemination have become useful means by which to build action in the Independent Living movement.

Knowledge Utilization with Accreditation of ILRCs

In North America, accreditation is a voluntary, non-governmental process of review. Typically designed as an external review of quality assurance, accreditation ensures that organizations uphold various standards. The Canadian association and its network of centres began to develop an accreditation process for centres in the mid-1990s. In traditional professions, accreditation is strongly linked with certification. CAILC focuses instead on providing support to centres as they learn and evolve. Michael Horne explains that, "Accreditation was seen as part of a long-term process of learning and development." Accreditation was originally in the CAILC bylaws but there was uncertainty in how to implement it.

The CAILC accreditation process describes how centres can build their capacity. Somewhat akin to developmental evaluation, the idea is to create learning opportunities for centres as they move from *centres-under-development* to *fully accredited centres*. "The process of accreditation is about people learning and growing," says Susan Forester, CAILC staff person who works with centres on the process.

Much of this process of learning and development was informed by the growing body of research about Independent Living and the role of ILRCs. In this sense, accreditation is very much about knowledge utilization.

In preparing their accreditation approach, CAILC staff worked with centres to be sure they would focus on whatever members thought was important. The accreditation process was created with the St. John Centre and tested in several pilot sites across the network. In the document entitled *Accreditation Tool for Independent Living Centres*, the following key objectives for the accreditation tool are outlined:

- It is concise and user-friendly;
- It is clear in content;
- Its approach and tone are consistent with IL philosophy;
- It is flexible enough to be relevant to and unbiased towards both larger and smaller ILRCs;
- It covers the main elements of an ILRC;
- It outlines standards that are consistent with those already in place or anticipated within CAILC and its member groups,
- It acknowledges effort as well as outcome.[3]

The national association committee selected eight categories for accreditation, based upon their review of other accreditation tools, input from the centres, and their own judgement. The categories chosen were:

1. Mission statement/philosophy;
2. Service design;
3. Service delivery;
4. Organizational structure;
5. Membership;
6. Administration;
7. Accommodation; and
8. External relationships.

The *accreditation tool* suggests there are higher and lower priority elements in terms of accreditation. Higher priority elements, which may exist in a number of the categories, include:

- A clear mission statement consistent with IL philosophy;
- Consumer control, cross-disability representation, and inclusion;
- Existence of staffing and activity in support of the four core program areas as described by CAILC; and
- Clear efforts to attract and serve a membership base.

These principles ensure that the Independent Living values are central to the accreditation process.

In developing a rating scale for the accreditation, CAILC again chose an approach that assists centres in their process of development. Ratings for each category are: *does not exist*; *not applicable*; *partial*; and *substantial*. As part of an accreditation report, these ratings are provided with explanation, thus giving the centres detailed feedback about their strengths and areas that could be improved.

The overall rating of an Independent Living Resource Centre will be one of the following:

- *Accredited:* The centre meets the standards to a reasonable degree, and any recommendations are generally minor in nature;
- *Provisionally accredited:* The centre meets most standards to a reasonable degree, but requires improvement to maintain its status in subsequent review;
- *Referred for further development:* The centre does not generally meet the standards or does not meet the essential standards, but demonstrates capacity and commitment to do so;
- *Not accredited:* The centre either does not generally meet the standards or does not meet the essential standards, and does not demonstrate the capacity and/or commitment to do so.

The national association occasionally asks all centres to undertake a self-assessment before they take part in the formal accreditation. This self-assessment is a form of research that produces knowledge that can be used in improving the operation of the ILRCs. During 2004–2005, each centre went through the accreditation tool to let CAILC know how they thought they were progressing in each of the eight categories that the tool addresses. This was done at each centre by setting up a working group, consulting with staff, board, volunteers, consumers, and, if possible, some community stakeholders. This exercise served as a dress rehearsal. By doing the self-assessment first, areas for improvement could be identified at least a year prior to taking part in the accreditation process. For one centre in western Canada, this self-assessment "provided good information and identified steady progress in all aspects of program development, design and evaluation, and organizational structure." In addition, the centre noted that they had "made great improvements over the past two years."

Centres report that they appreciate the developmental nature of the accreditation process. The focus on the organizational and service components as separate from individuals is also seen as a strength. Some leaders admit there are accreditation issues that need sorting out. As one person emphasized, "Since CAILC is now both the funder and the accreditation body, it is sometimes confusing how best to relate to them." Typically, these functions are separate, as in the case of universities and colleges. Although the developmental nature of the accreditation reduces some of the stress of "making the grade," others say that the standards should be applied more stringently.

The challenge for the national association is to use their accreditation process in ways that create useful feedback for centres. As Margaret Wheatley has written, "We would like to dethrone measurement from its godly position, to reveal the false god it has been. We want instead to offer measurement a new job—that of helpful servant. We want to use measurement (and evaluation) to give us the kind and quality of feedback that supports people to step forward with their desire to contribute, to learn, and to achieve."[4]

Some people in the Independent Living movement express concern that accreditation by itself does not encourage innovation. Typically, a standards approach focuses on elements and procedures that ensure the organizational basics are in place. As one leader says, "By doing this, we are professionalizing the movement." Progressive organizations recognize that they need other strategies to keep innovation alive in their organization. Some leaders say that accreditation creates the foundation for effective organization culture, and that the right people and the right projects create the possibilities for ongoing innovation. As we have seen, many centres have been able to maintain a degree of innovation, while accreditation insures that all centres work toward a cross-Canada standard in the key areas of philosophy and programming.

Focus on Community Mobilization and Research

Research and community development is currently a core program of Independent Living Resource Centres. The twinning of research and community development within centres is a unique concept in the non-profit sector. Most human service organizations have mandates only for service delivery. Pierre Majeau from the Montreal Centre points out that centres must be able to "test out" different ways of meeting needs that are currently unmet, poorly met, or met in a way inconsistent with the IL philosophy. In addition, research and community development as a core program helps people sort out what is working well and what is not working. This has created a broad base of evidence for the main Independent Living approaches and has greatly influenced their development. Some centres have built strong research and community development capacity that enables them to maintain innovative approaches to their work.

In many ways, much of the research completed at centres is designed to mobilize people around a particular issue. We can see that research and community mobilization at ILRCs usually takes one of two forms. In the first, a new idea is tested out with current consumers, usually in response to demands of members. In the second, a well-developed idea is used with new consumers, people who typically have not made use of the centre in the past. We share examples from each of these strategies.

Several centres across Canada have initiated research and community development projects *in response to their members* and often related to a window of opportunity that exists for innovation. Such was the case with the Victoria Disability Resource Centre, when they initiated a research project on entrepreneurship in employment. Staff at the centre had noted the growing interest of consumers in self-employment and entrepreneurship. In collaboration with CAILC and funded by the federal government's Opportunities Fund, this research project connected the centre with other generic employment providers and with consumers who were interested in self-employment. The outcome of this research and development was a growing interest in self-employment. The Victoria Centre then began coaching, mentoring, and providing ongoing support and workshops on self-employment. This initiative of the Victoria Centre has more recently become part of the Sustainable Employment Network, a partnership of four organizations that provide a range of supports to people with disabilities who are interested in self-employment. The Victoria experience is typical of many research and community development projects where a new initiative emerges out of the research.

In the year 2001, Kier Martin was hired as a youth intern with the Independent Living Resource Centre in St. John's to respond to growing consumer interest in computer technology. The goal of the 12-week placement was to assist people with the exploration of computers and the Internet. When he started this work, Martin was aware of the digital divide between people who can access computer technology and people who have no access. However, as Martin began to research adaptive technology and to download some of it for consumers to explore, he was amazed at the resources that were available! "This short initiative demonstrated that IL and technology work together, which was proven by the creation of the provincial adaptive technology program," says Martin.

When the 12-week development project was ending, the St. John's Centre had a "consumer uprising" and demands were made for the initiative to continue. As a result, adaptive technology became an important program, and within two years of the initial pilot, the centre received provincial funding to make computer technology accessible to all citizens with disabilities in Newfoundland and Labrador. Kier Martin describes how the St. John's Centre also learned how to assist consumers with computer technology. "We learned to ask the IL question, 'How do you want to use this technology?' as opposed to telling people 'This is how you use it.'" Today, the St. John's Centre is thriving in this area, not only assisting people with disabilities, but also helping other organizations become effective with adaptive technology.

Through recognition of the increasing role of technology at St. John's and other centres, national projects such as the Virtual Independent Living Resource Centre initiative emerged to highlight future directions and demonstrate an Independent Living approach with technology initiatives. This developing area may become a new core program and will be discussed further in Chapter 13.

The Trois-Pistoles Centre has utilized research and community development with *new consumers* in a number of ways. Carole Sénéchal, its chair for 15 years, describes the way that the ILRC has played a very significant role in this area. "Two projects—seniors' abuse and daycare—have had a very positive impact on the ILRC," she says. "They made the centre and the entire philosophy known throughout the region…. Nothing had been done in the area of seniors' abuse prior to our involvement. Our project was a first, and made it possible to produce documents and to chart a course in this area. This was very positive for the ILRC." Sénéchal adds that, "Research and development is an aspect that sets the Independent Living Centres apart from other agencies because research, needs analyses, and things like that have been integral to our centre's work and have had a fairly significant impact."


Carole Sénéchal

Trois-Pistoles has had impressive involvement in research. Their 2006 research on employment has raised serious issues about the impact of how people with disabilities are represented in the workplace. The study, *Impacts of Social Representations*, shows that most employers perceive people with disabilities as limited, under-qualified, and requiring much accommodation and supervision. This study has been influential in the Bas St. Laurent area of Quebec and more recently across Canada as other centres have used the study to enhance their employment work. The study includes an action plan on ways to promote the inclusion of people with disabilities in the labour market.

The Kingston Independent Living Centre spearheaded a feasibility study on evaluation in 2001. With a national advisory committee of CAILC board members and ILRC executive directors, the feasibility study produced a report entitled *Developing Effective Practices in IL Evaluation* that highlights surveys with other centres, focus groups with consumers, and recommendations for how evaluation can be carried out within an Independent Living framework. This report formed the foundation for CAILC to develop the details of its IL Impact Project, to be explored in Chapter 10. Like so many national initiatives, the role of evaluation was first explored within the context of a centre. As they demonstrated how to build research capacity, the Kingston Centre's report became a catalyst for a major national project. This experience is an example of how local research can have influence far beyond one local centre.

Incrementalism: Government Policy Gradually Embraces Independent Living

Some Canadian researchers have described Canada's approach to social policy development as a process of "incrementalism."[5] In social policy, incrementalism refers to the enactment of small policy changes over time designed to contribute to a larger policy framework. One study examined Canadian and provincial government budgets over a period of more than 30 years and found that "incremental decision making" was the dominant approach to policy making.[6] The federal and provincial governments' approach to policy making related to Independent Living certainly fits with this idea of incrementalism.

There is research evidence to show that over the years, the federal government has been influenced by Independent Living. The government's own 1997 report on *Lessons Learned: Disability Policies and Programs* outlines the value of an Independent Living approach applied to disability and policy. This report states that, "Services based on Independent Living principles are more effective…than traditional services."[7] With small incremental steps over the years, the government's commitment to Independent Living has grown. More recently, the federal government has drawn on IL research in some of its own documents. Despite increased understanding of Independent Living at the federal level, funding has not increased to keep pace with the growth of centres.

In 1999, a professor from Wilfrid Laurier University in Waterloo, Ontario, completed a major research study entitled *The Development of Government Independent Living Policies and Programs for Canadians with Disabilities*. Peter Dunn, a professor of social work and the report's author, had studied in the United States with Irv Zola, and understood the power of the Independent Living philosophy. Table 41 summarizes some of the findings from the study completed by Dunn and his colleagues.

Table 41

The Development of Government Independent Living Policies and Programs for Canadians with Disabilities: Summary of Findings

---

This comprehensive research study examined differences in the extent and quality of government policy efforts in Independent Living. A number of variables were examined, mainly during the Decade of Disabled Persons (1983–1993) and beyond. Ten separate questionnaires were constructed and sent to a wide range of governments and non-profit organizations.

The results of this study identified some positive trends and indicators that show that provincial and federal governments have been gradually moving toward the principles of Independent Living in their policies. Examples include:

- *Barrier-free housing:* Almost all provinces adopted the National Building Codes and most created their own housing adaptation programs. The study also found that many barriers to accessible housing still exist.
- *Accessible transportation:* Provinces increased their budgets regularly for parallel, specialized transportation. Some provinces and municipalities have begun to introduce accessible buses for all citizens. The study found that many barriers to accessible transportation still exist.
- *Personal supports:* Home support programs and attendant services expanded. Funding for disability supports increased dramatically. All provinces offer individualized funding for some citizens with disabilities. The study found that this area is very fragmented for consumers and families, and that many people remained in nursing homes and other institutions.
- *Innovation:* Most provinces were beginning to explore innovative approaches that included consumer control, in areas such as attendant services, individualized funding, and brokerage supports. These innovations were often started as pilot projects and were not widespread. Innovation was also present in public transportation, with some provinces moving to make all public transportation accessible.

Consistent with incrementalism, Peter Dunn's study shows that federal government expenditures related to Independent Living increased through the Decade of the Disabled (1983–1993), but then declined with government cutbacks in 1996. In reflecting on his study, Dunn says that in terms of the influence of Independent Living, "Ideas have been as powerful as programs." Although funding increases for federally funded programs have been inconsistent, Dunn points out that Independent Living principles have influenced the types of government expenditures over time. "We learned that IL principles have continued to evolve, despite cutbacks at certain times," says Dunn.

From his research, Peter Dunn highlights how the influence of Independent Living research and practice on federal and provincial government policy has been both direct and indirect. Direct influences relate to policies that have put Independent Living principles into operation. For example, in 1986, the federal government changed the Residential Rehabilitation Assistance program to be more flexible and easier to access for people with low to moderate incomes.

Dunn says that indirect influences are not always reflected in government funding, but that "trends we tracked over fifteen years clearly indicate that new initiatives by government often have an Independent Living frame." Dunn emphasizes that these trends are reflected nationally and provincially and are not tied to particular political parties in power. "They are, however, tied to the economy," explains Dunn. "Wealthier provinces, such as Ontario, Alberta, and British Columbia, reflect Independent Living in the most direct ways." Examples might include accessible transportation and even direct-funding programs for disability supports.

Despite the trends in Peter Dunn's research, some consumer leaders point out that the influence of Independent Living on federal government policy has not been particularly promising. One dilemma, they say, is the size of the government; there is no single point to influence, since many cabinet ministers and departments deal with disability in some way. They also note that although disability leaders have been quite involved in government consultations, there has been limited impact on federal policy. Leaders admit that the development of the Office of Disability Issues has been a helpful resource and contact for the national association.

At the same time, federal government officials now see CAILC as an important player on disability issues. For its part, CAILC has become sophisticated in lobbying with the federal government.

One of the promising areas that the Office of Disability Issues was facilitating in recent years was meetings of the Federal, Provincial, and Territorial Ministers on Social Services. In 1997, this group published *In Unison: A Canadian Approach to Disability Issues*, which highlights the values and principles of a citizenship approach to disability supports. Despite being forward-looking, this document has proven to be limited as a framework for transformation and systems change. Various federal governments have been unable to create an agreement with provincial governments that might have produced a real impact on disability supports and employment supports. As Fraser Valentine points out, "Independent Living outcomes are uneven because each provincial jurisdiction is different."

Although some provincial governments have been gradually embracing Independent Living principles, this has yet to translate into provincial funding for the ILRCs. To date, only three provinces (Newfoundland and Labrador, Manitoba, and British Columbia) have provided funding directly to centres. In addition, centres in Ontario do receive funds for providing regional planning and coordination for the Direct Funding Project for attendant services. Direct funding can serve a variety of people with disabilities and is designed for disability support dollars to go directly to the person, rather than through a transfer payment agency. Table 42 outlines the strengths and impacts of the Ontario Direct Funding Project. It is an excellent example of Independent Living research and principles having a direct impact on policy change.

Table 42
Ontario Direct Funding Project

In the mid-1980s, the Attendant Care Action Coalition in Ontario began advocating for a province-wide attendant service project that would include individualized funding. The coalition argued in several briefs to government that people who required attendant services should have the right to direct their own care.

The only way this could happen effectively, they said, would be to create a project with direct funding as the core idea. A research study commissioned by the Ontario government, *Independence & Control: Today's Dream, Tomorrow's Reality,* was released in 1989 and made the same recommendation.[8] The outcome of this advocacy and research was the new Ontario Direct Funding Project, which came into being in 1993 with the passage of new long-term care legislation.

Leaders in the Ontario Independent Living movement played a central role in the development of the Ontario Direct Funding Project. Because of their leadership, the Centre for Independent Living Toronto became the administrative body of the project and the other nine centres in Ontario were funded to provide information and planning support for consumers who wanted to apply for direct funding. Having this unique initiative located within Independent Living Resource Centres has had many positive impacts on consumers and communities across Ontario.

The first and most important impact is the power shift that has occurred in the way attendant services are provided. The Direct Funding Project gives consumers the right to self-direct and self-manage their lives and the supports they require. Vic Willy, program administrator, says this has profound impacts: "A person who does not have the option of control over his attendants, when they show up, and what they do, is in a very vulnerable position and is not getting his rights as a citizen." Furthermore, Willy says that the control the consumer has in this program is crucial: "Don't talk to us about how we can avoid abuse, have equal opportunities, and get to work on time unless you're willing to talk about our means to control our lives. Self-management gives us this."[9] The impact of this power shift has meant that centres have a means to encourage and support consumers to pursue individualized funding when appropriate. Direct Funding and Independent Living are a perfect fit, and this infrastructure within centres has created opportunities for self-determination and citizenship to be experienced in a very practical way.

At the same time, several provinces have begun to transform their disability supports by creating vehicles for people to access individualized funding and independent planning and facilitation. British Columbia, Ontario, and New Brunswick are all moving ahead in these areas, with BC demonstrating the most innovative approaches to date. Many of these transformation ideas are explored in *Pathways* *to Inclusion: Building a New Story with People and Communities,* a 2007 book by John Lord and Peggy Hutchison.

The 1996 Federal Task Force on Disability Issues

Over the years, the Independent Living movement has been instrumental in influencing federal government policy and directions. In the 1980s, Independent Living leaders played an important role in the development of an agreement between CAILC and the federal government. In the mid-1990s, the federal government was cutting programs and services in order to reduce the national deficit. In that climate, the House of Commons Standing Committee created a task force to review the needs of persons with disabilities. CAILC would once again play a key role in this important federal task force.

The task force decided to tackle the question, "Why should the federal government be involved in disability issues?" Realizing the need to ground this work in the disability movement, Member of Parliament Andy Scott, chair of the task force, invited Traci Walters, national director of CAILC, and two other national disability leaders, to become observers and consultants to the process. Walters' involvement turned out to be very important. She and the other observers played a significant role in setting the tone for deliberations. As the task force members travelled across the country, the observers had an ongoing dialogue with the four MPs who were leading the task force. Walters and other consumer leaders were also able to share Independent Living research and ideas with the task force members. Meeting with Canadians with disabilities from all parts of Canada, task force members also heard the voices, stories, and concerns about the struggles people often face.

The task force submitted its report *Equal Citizenship for Canadians with Disabilities: The Will to Act* to parliament in October 1996. The report reasserted disability as a federal responsibility, particularly based on citizenship and human rights. The report also made substantial recommendations related to cost of disability, employment, disability income, and the role of the federal government. Although few of the recommendations were acted on immediately, the report created a framework for the disability movement to advocate with the federal government to implement its own directions.

For CAILC, the task force experience established Independent Living as a central idea for citizenship and people with disabilities in Canada. Many of the presentations to the task force were framed in terms of Independent Living. The presence of Traci Walters during proceedings lent further credibility to the movement. Even though federal cutbacks in the mid-1990s created hardship for many Canadians, Independent Living as a movement did not lose significant ground. In fact, the citizenship framework of the Scott task force created future opportunities for the movement. Traci Walters explains why Independent Living is a good fit with a citizenship agenda: "As one example, information and networking provides people with information that enables them to be full citizens." Furthermore, she adds that, "Research and development is a key function within centres that fits well with many federal jurisdictions."

Influencing Municipal Government Policy

We have already noted in previous chapters some of the ways that centres have influenced municipal initiatives and policy. Centres do seem to form relationships with local politicians and municipal staff more easily than other levels of government. For example, Richmond, BC, has been named the most accessible city in Canada. Vince Miele from the Richmond Disability Resource Centre explains how they have played a major role in helping Richmond receive this honour. "Over the years," says Miele, "our group has been able to keep the city council's feet to the fire." The Richmond Centre is actively involved in the approval of plans for the city, and is represented on a city planning committee and advisory panel. Miele notes that, "We assist with universal design, and in terms of policy, we keep in touch with what is going on."

Summary and Reflections

Research capacity and policy development play important roles in advancing the Independent Living movement. The core program of research and community development within Independent Living Resource Centres is unique in the non-profit sector and contributes to ongoing learning and innovation. Research at centres usually takes one of two forms. In the first, a new idea is tested out with current consumers. In the second, a well-developed idea is used with new consumers, people who typically have previously not used the centre.

The national association's interest in building research capacity has been shared by other national disability organizations. In 2006 and 2007, CAILC collaborated with four other national organizations to work on a project entitled *Enhancing the Research and Knowledge Mobilization Capacity of Disability Community Organizations*.[10] The Centre for Community Based Research worked closely with the national partners to create a set of principles and recommendations for enhancing disability-driven research capacity. All partners agree that a national entity is needed for setting research agendas, creating an information policy network, and brokering research relationships with other partners.

Government policy development related to Independent Living in Canada has reflected what has been called incrementalism. Incremental change can be constructive, since change is seen as positive and it can occur step by step, year by year. The dilemma with incremental change is that you tend to get more of what you already have. Some social change theorists argue that it is exponential or transformative change that is needed to enhance innovation and the development of new ideas. As Bruce Anderson writes in *The Teacher's Gift*, such change will result in large shifts in direction, but may also come with people who are against the change pushing back.[11]

Rarely do governments support exponential or transformative change. This has created a dilemma for the Independent Living movement that has to rely on incremental change to achieve what it requires from governments. As we shall see, this reality has also forced the national association and its network of centres to seek funding and support from other sources in addition to governments.

Table 43 outlines the way the national association and its centres have built research capacity and use research to influence social policy. It also summarizes some of the ways that research and policy have contributed to the awareness and expansion of Independent Living in Canada.

Table 43
Research Capacity and Policy Development: Role and Influence of Independent Living

1. Research plays several roles within the Independent Living movement, including knowledge production, knowledge dissemination, knowledge utilization, and community mobilization.
2. It took CAILC and its network of centres sometime in the 1980s to find research approaches that were a good fit with Independent Living. Participatory action research is now embraced by the movement as an approach to research that empowers consumers and keeps control of the research in the hands of consumers. CAILC has developed a framework and guidelines for community research and Independent Living.
3. The core program of research and community development within ILRCs is unique in the non-profit sector and helps ensure that centres continue to learn and be innovative.
4. The development of fact sheets by CAILC has been an important tool for influencing thinking and policy development. The fact sheets highlight research findings in various areas, such as accessibility, and propose recommendations for change. They are an excellent example of knowledge dissemination.
5. Accreditation was adopted by CAILC and its network of centres as a way to enhance learning and development of centres. Accreditation is a helpful approach for providing feedback to centres in their process of development. It is an excellent example of knowledge utilization.
6. Federal and provincial government policy in regard to Independent Living can be characterized as incrementalism. Research shows that government policies have been shifting slowly toward Independent Living principles over the last 20 years. Leaders in the movement recognize the strengths and limitations of incremental approaches to policy development.
7. Independent Living Resource Centres have had influence on municipal government policies in practical ways that include areas such as local accessibility.

Twenty-five years of the Independent Living movement have established a set of sound research guidelines and practices, as well as government policies that have been slowly moving toward Independent Living principles. Although some would say this work represents "best practice," the IL movement has been reluctant to use such definitive language. A national think tank rejected the language of best practice and suggested that "effective practice" was more modest and suggested room to grow and change.

The reality in Canadian disability policy is that we have a long way to go before policy truly reflects Independent Living principles. The disability movement is well aware that holding the values and principles of Independent Living is only the beginning. Moving the values and principles into research, policies, and practices that can transform the lives of citizens with disabilities is the work that will continue for years to come.

> *I make a fortune from criticizing the policy of the government, and then hand it over to the government in taxes to keep it going.*
>
> —George Bernard Shaw

Endnotes

1 Sandra Carpenter, "Independent Living Centre Perspective on Cross-Disability and Consumer-Control," in *Independent Living: An Agenda for the '90s,* ed. Canadian Association of Independent Living Centres (Ottawa: CAILC, 1993).

2 Gary Woodhill, *Independent Living and Participation in Research: A Critical Analysis* (Toronto: Centre for Independent Living Toronto, 2002), i.

3 CAILC, *Accreditation Tool for Independent Living Centres* (Ottawa: Canadian Association of Independent Living Centres), 16.

4 Margaret Wheatley, *Finding Our Way: Leadership for an Uncertain Time* (San Francisco: Barlett-Koehler, 2005), 162.

5 See, for example, Michael Prince, "The Return of Directed Incrementalism: Innovating Social Policy," in *How Ottawa Spends 2002–2003: The Security Aftermath and National Priorities,* ed. G.B. Doern (Toronto: Oxford University Press, 2001), 176–195.

6 Christopher Reddick, "Long-Term and Short-Term Budgeting: Theories and

Empirical Evidence for the Canadian Provinces,' *International Journal of Public Administration* 26, no. 4 (2003): 427–453.

7 Human Resources Development Canada, *Lessons Learned: Disability Policy and Programs* (Ottawa: HRDC, 1997), 13.

8 Attendant Care Action Coalition, *Flying on Our Own Conference* (London, ON) *Proceedings*. (Toronto: Attendant Care Action Coalition, 1990).

9 Ian Parker, Hazel Self, and Vic Willy, *Power Shift* (Toronto: Centre for Independent Living Toronto, 2000), 2.

10 Centre for Community-Based Research, *Enhancing the Research and Knowledge Mobilization Capacity of Disability Community Organizations* (Kitchener, ON: Centre for Community-Based Research, 2007).

11 See Bruce Anderson's website [www.communityactivators.com].

Chapter 10

National Independent Living Initiatives: Effects on the Movement and Beyond

Canada is an expansive country with ten provinces, three territories, and oceans on three sides. With 32 million people, Canada's population is spread out from coast to coast. Although funding for most disability issues is the responsibility of the provinces and territories, Canada's federal government has played a major role in seeding national disability initiatives. These national projects have been very important in contributing to the capacity building of the Independent Living movement. Most national Independent Living initiatives have involved partnerships with non-disability organizations. As a result, national initiatives have also been able to have an interesting ripple effect with mainstream organizations and structures.

One overall purpose of national initiatives is to enhance understanding about Independent Living and its application to a variety of contexts. National initiatives are also designed to support Independent Living Resource Centres (ILRCs) to build their capacity to be sustaining organizations and to partner with a range of people and organizations in their communities.

Over the years, this dual purpose of national initiatives has led to two kinds of national projects initiated by the Canadian Association of Independent Living Centres (CAILC). The first type of initiative involves CAILC working in collaboration with its centres and other sectors of society to address an issue of national and local concern. The second type of initiative involves projects designed specifically to enhance the sustainability and capacity of centres. In this chapter, we examine both types of national initiatives that have had an impact on the Independent Living movement and beyond.

National Initiatives: Partnerships Between ILRCs and Mainstream Organizations

As we have documented, by the early 1990s the Independent Living movement was becoming well established in Canada. In 1993, CAILC received funding for a national initiative, the Family Violence Project. Leaders saw this initiative as an opportunity for CAILC to lead a national initiative in collaboration with its network of centres and other mainstream organizations. The Family Violence Project would be the first of several national initiatives designed to promote Independent Living for a specific issue that concerns the local centres as well as other sectors of society. Several themes and lessons emerge from the experience of these national projects.

First, there is power in purpose. CAILC learned very early on that national initiatives must have a clear purpose that everyone can understand and get behind. This is evident in both the Family Violence Project and the Crime Prevention and Independent Living Initiative done later by the national association. An example of the purpose and objectives of Crime Prevention Initiative are outlined in Table 44.

Table 44
Crime Prevention and Independent Living:
A Pan-Canadian Initiative for People with Disabilities

The purpose of this initiative was to build capacity of local disability organizations, including the national network on CAILC member Independent Living Resource Centres, first time responders, and local communities to work together and share information on crime prevention programs and initiatives for people with disabilities.

There are three central objectives of this initiative:

1. To highlight the particular circumstances of crime and victimization towards people with disabilities in Canada through increased sharing between and among law enforcement agencies, disability organizations, service providers, and people with disabilities;
2. To develop information, resources, and dialogue about crime prevention and disability; and
3. To develop and enhance networking and partnerships at the local and national levels between law enforcement agencies, front-line workers, disability and community organizations, ILRCs, and persons with disabilities.

Leaders report that a clear project purpose inspires centres and their local partners to work together and to find common ground to address problems that are of concern to both partners. As another example, the purpose of the Healthy Lifestyles Project, a partnership between CAILC and the Active Living Alliance of Canadians with Disabilities, was to enhance the capacity of ILRCs to develop healthy lifestyle programming. Partnerships with clear purpose enhance the capacity of local centres and the national Association.

Crime Prevention Symposium in partnership with Ottawa City Police

Second, it is important to share information broadly and to communicate effectively. Leaders connected with national initiatives soon learned that information and knowledge are key to understanding and involvement. In some cases, this involved sharing statistics about the impact of the issue on people with disabilities and the wider community. CAILC's first national literacy project highlighted the fact that 50 percent of people with disabilities experience literacy barriers. Similarly, the crime prevention project showed that two-thirds of all women with disabilities have been physically or sexually assaulted before adulthood and that Canadians with disabilities are twice as likely to be victims of violence. These stark statistics, when combined with communiqués about general strategies for change, were often quite compelling. Michael Horne, national staff person at the time, says the Family Violence Project was "groundbreaking because it got disability out of the closet and onto the table. It broadened the definition of family violence." For people with disabilities, this may include violence at the hands of support workers or attendants, for example. Clear communication helps build interest in important social issues, identifies gaps in thinking and action, and creates momentum for change.

Fact sheets have been an important part of sharing information within national initiatives. A recent example of this is CAILC's Access to Recovery: Substance Use/Misuse and Independent Living Project, which aims to increase education and awareness on the issues related to this topic and the removal of barriers to persons with disabilities and mainstream service providers alike. In the first phase of the Access to Recovery Project, started in 2006, six fact sheets for recovery professionals and five others for consumers were developed. Each of these fact sheets were based on research completed on recovery. Fact sheets for consumers included such issues as harm reduction and prescription drugs and drug interactions. Fact sheets for professionals included issues such as substance abuse and disability, as well as physical accessibility. These fact sheets created broad awareness and understanding as the basis for the project moving to the second phase of development.

Table 45 outlines some of the ways that research and development has been utilized in national initiatives. Effective research and development often form the basis of communication in national initiatives.

Table 45
Research and Development:
Its Role in National Independent Living Initiatives

National initiatives have benefited immensely from research and development. In the early stages of these projects, CAILC and its network carry out a number of research and development activities. These include:

- Gathering and sharing statistics on the issue (literacy rates, crimes against people with disabilities, etc.);
- Gathering stories and experiences of people with disabilities (the lived experiences of people themselves present powerful insights);
- Conducting literature reviews and inviting leaders in specific issue areas to share what others have done (searching for best practice). This involves valuing IL leaders and sharing expertise with the mainstream and non-disability organizations;
- Holding forums where participants can explore what this issue means in terms of Independent Living (forums begin the process of collaboration and partnership building between centres and mainstream groups);
- Building sustainable partnerships based on common understanding of research and development.

Third, genuine collaboration enhances the likelihood that impact from national initiatives is felt beyond the Independent Living movement, and promotes the inclusion of people with disabilities in mainstream services. Each of these initiatives was designed to build partnerships with a broad sector of society that might be concerned with the issue. The first national literacy project included a training institute that brought literacy providers and staff from centres together. One person reported that "the enthusiasm of participants at this event was very high." Because of sustained collaboration, several outcomes resulted from that project, including the development of a national website called Literacy for Independent Living. This website, a legacy of the national project, continues to be well used by the disability community and literacy providers across Canada.

Genuine collaboration means people coming to the same table with a commitment to participate and learn together. Michael Horne participated in several national projects and notes that CAILC always started with two assumptions. "We believed," says Horne, "that everyone has something to offer and that an Independent Living lens is a critical guide to deliberations."

A National Safety Symposium, held in Ottawa in 2005 as part of the national Crime Prevention Initiative, demonstrates how collaboration has had ripple effects well beyond the Independent Living movement. This symposium was co-sponsored by CAILC, the Ottawa Police Service, and the federal government. Symposium participants, representing a broad range of stakeholders, came up with a number of key directions for change. Even though the project has ended, there are indications that several groups are continuing to work on these directions, including some crime prevention councils and even police chiefs. Within a year of the symposium, the Canadian Chiefs of Police hosted two Community Safety Round Tables and invited a broad range of non-profit sector groups to attend. These events built on the collaborative events that CAILC had hosted as part of the Crime Prevention Project.

Our understanding is that complex social issues, such as literacy, family violence, access to recovery, and crime prevention, require comprehensive thinking and multi-sector collaboration. Recent research shows that when stakeholders are invited to work together on a social issue, positive results can accrue. The Canadian national Vibrant Communities Project, for example, includes six major local projects all focused on reducing poverty. After three years, the project is showing very positive results. One reason is that the commitment to grow a diverse range of leaders from various sectors who are working together to build the capacity of communities to resolve issues of poverty.[1]

Centres report that relationship building is key to collaboration with mainstream organizations. Centre staff members often spend a lot of time in dialogue with mainstream organizations. In the Access to Recovery Project, for example, the “train the trainer” approach connects mentors from centres with mainstream recovery professionals. Building local steering committees also helps to create space where people work across differences and find common ground.

In describing one of the family violence committees, Michael Horne says, “Everyone was perceived to be an expert because they had lived the experience. The project did not need a professional lead because everyone contributed.” Finding common ground is enhanced when local centres and mainstream organizations work respectfully together and focus on solutions. Typically, projects make use of participatory action research to build this collaboration. People involved in such research often become ambassadors in collaborative initiatives, helping to spread the impact beyond the Independent Living movement.

Partnerships— Leaders of the Trois-Pistoles Centre with former HRSDC minister Ken Dryden

Fourth, national initiatives take a solution-based approach to issues that are a concern to the Independent Living movement and to mainstream organizations. National projects typically identify a social issue that requires collaboration among disability and mainstream organizations. A solution-based approach to these issues means that the groups work collaboratively to find practical solutions. In seeking practical solutions, however, Traci Walters from CAILC reminds us that values and principles guide any proposed solutions. The Crime Prevention and Independent Living Initiative, for example, was guided by several core beliefs and principles, including the following:

- The right to be treated with respect and to live free from mistreatment in safety and security;
- A cross-disability focus;
- Continuous learning through diverse methods (for example, dialogue, role play, workshops, and reading);
- The input of people with disabilities in professional development is valued, welcomed, and facilitated.

It is also interesting to see how national initiatives check in regularly with the values and principles as a way to keep their project on track. These check-ins, often in the form of conference calls, provide an opportunity for local projects to raise any tensions or issues with which they may be struggling.

With values and principles as a foundation, the focus of community collaborations is on solutions. Michael Horne says that a solution focus pulls people to a new level of confidence in understanding barriers facing people with disabilities. “Vulnerability is often very deep,” says Horne, “and these collaborative projects enable us to focus on multi-level solutions.” The Crime Prevention Initiative created avenues for the police to learn more about the violence against people with disabilities and to be part of creating community solutions. The project also recommended a number of policy-level solutions designed to strengthen laws and procedures. Similarly, the Access to Recovery Project learned quite early that there are several little things that professional organizations can do to improve access for people with disabilities.

Fifth, the engagement of consumers is central to project development and implementation. By using Independent Living as a lens, national initiatives engage consumers as leaders and participants in each project. The presence of people with disabilities in leadership roles helps mainstream groups reframe their thinking in regard to the issue. Literacy group representatives at a 2005 CAILC-sponsored national conference on Literacy and Independent Living indicated how much they appreciated the leadership and participation of the participants with disabilities. In all projects, consumers with disabilities ground everyone in the real issues. When women with disabilities told their stories about violence they had experienced as part of the Crime Prevention Initiative, it had a profound impact on other participants.

Sixth, the development of useful resources and products is an important outcome of national initiatives. Because national initiatives are time limited, usually two to three years, the development and distribution of resource materials is one of the important legacies of these projects. The Independent Living and Literacy website, one of the literacy project's products, is well used by disability and non-disability groups. The Healthy Lifestyles Project has created educational materials for consumers, recreation facilities, and other organizations concerned with healthy lifestyles and universal design. The three centres that were involved with the Family Violence Project created manuals for distinct populations. The *Centre-Ressources pour la Vie Autonome Région du Bas-Saint-Laurent* in Trois-Pistoles created materials for working with seniors in a rural area, and ILRC Calgary created a manual on reducing family violence with an Independent Living approach. Similarly, the Access to Recovery Project is producing tools and resources that will help communities to implement a prevention and promotion strategy with an inclusion and Independent Living frame.

Other national initiatives have created national reports that summarize lessons learned and make recommendations for future initiatives. The conference proceedings of the Crime Prevention Initiative have a number of suggestions for follow-up work. Several crime prevention councils across Canada have taken these recommendations and worked on implementation. Finally, some projects have benefited from national evaluations that create ideas and directions for follow-up resources and directions. Navigating the Waters, the CAILC national employment initiative, had feedback from a national evaluation for three separate years. These newsletter evaluation reports were very helpful for centres as learning and information resources. Several centres used this research and evaluation material to assist them in building a case for the continuation on their project with other funders. Because entrepreneurship was identified in Navigating the Waters as important to Canadians with disabilities, CAILC worked with researchers and several centres across Canada to carry out a study on entrepreneurial services. This team produced a very useful resource guide, entitled *Best Practices for Delivering Entrepreneurial Services to Canadians with Disabilities*.

Seventh, national projects have enabled the national association to test the application of the Independent Living approach with a range of populations and issues. Although Independent Living has clearly benefited citizens with disabilities, the national projects have contributed deeper insights about specific sub-populations and issues. Both the Family Violence and Crime Prevention Initiatives, for example, highlight dilemmas facing women with disabilities. These projects show the importance of paying attention to gender issues, vulnerabilities, and the protection of the rights of women.

The Opening Doors Project, funded by Corrections Canada and carried out by the Halifax Independent Living Resource Centre, was an application of the IL approach to people with disabilities who were transitioning to the community from a correctional facility. The evaluation of the project was very positive and showed that the Independent Living philosophy could be applied to what is typically thought of as a challenging area. Unfortunately, despite a very positive evaluation that included consumer accounts of life-changing impacts and useful statistics, the government could not access funds to implement it nationally.

As another application, several centres, including Winnipeg and Trois- Pistoles, have done extensive work in applying the Independent Living philosophy to working with senior citizens. Given our aging society, this is likely to have fruitful and broad application of Independent Living in the future.

As we have seen, centres have very successfully applied Independent Living to the area of employment. Beginning with Navigating the Waters in 1997, centres learned that they were very well suited to provide career development and employment support. Several insights were identified in the Navigating the Waters evaluations, and one in particular is noteworthy. Facilitators within centres were found to be very helpful in the process of career and employment development. Facilitators met with individuals, helped people develop career goals, and provided support for people to connect with training or workplaces of interest. Consumers said they appreciated the facilitators and their skills of listening and facilitation. Centres report that this concept of facilitation has broad applications with Independent Living and other areas of disability. Consumers often find they require facilitation, whether for planning, employment, housing, or a host of other personal and social issues.

National Capacity Building Projects for CAILC and Centres

During the first few years of the Canadian Association of Independent Living Centres (CAILC), the national body served primarily as the administrative arm of the centres. As we have seen, national projects helped cement CAILC's role as facilitator and leader of the Independent Living movement. By the late 1990s, national director Traci Walters and the CAILC board realized that CAILC and its network also needed to build their own capacity if they were to be sustainable for the long term. Two major national initiatives would have an enormous impact on the national association and the Independent Living Resource Centres.

In 2002, the board of the national association decided to develop a comprehensive business case for its next five years. The idea to do this planning was based on several concerns expressed within the movement and noted by the Canadian government, CAILC's largest funder. The national association had been very successful in growing the movement during the previous 15 years, with expansion going from six to 26 centres during that time. Nevertheless, CAILC noted that several centres were facing a number of weaknesses common to evolving and underfunded organizations. It was recognized that the application of core programs across centres was quite inconsistent and that funding was indeed limited. At the same time, government was telling CAILC that they needed consistent reporting information from across the country.

The purpose of the business case was to outline a vision for the future, propose a new governance structure, and create a plan whereby the national association and the federal government could expand their partnership in new ways. Paul-Claude Bérubé, CAILC chair at the time, has written about how important it was to involve members in the process of building the business case. "CAILC developed this business case thorough a highly inclusive and democratic process to ensure maximum relevance and coherence from within the IL movement," Bérubé wrote.

CAILC worked with several leaders in the movement, who formed a national advisory committee. Each of the then 26 centres provided input and ideas at each step of the process, and the CAILC board played a key role in synthesizing the ideas that were generated. Although there was some resistance at first to creating a national plan, because some centres were opposed to using a business model for Independent Living, the high level of participation of members reduced the conflict. In reflecting on the process, national director Traci Walters says, "The involvement of people from across the movement showed the power of the IL network and allowed people to share their skills in meaningful ways."

When the business case was released in 2004, it became a catalyst for change in the partnership between the national association and the federal government. "It was," says Paul-Claude Bérubé, "an important document to guide us toward the future." Board members were very pleased that they now had a document that gave direction and vision for the future. Centres report that they now have a stronger relationship with the national association because the business case clearly reflects their own needs and aspirations. The development of this national vision and set of strategies was clearly collaborative and consistent with the way CAILC had tried to

IL Canada Board of Directors meeting, 2008

implement their other national initiatives. One leader noted that, "the Business Plan creates the possibility that we can begin to truly build the capacity of our centre."

The essence of the business case included several new strategic directions:

- Develop the capacity and leadership of CAILC and its network of centres;
- Enhance Independent Living professional and best practices;
- Enhance CAILC coordination and administration;
- Explore the capacity of centres to expand partnerships and strategic alliances;
- Increase community outreach and awareness; and
- Expand and enhance the Independent Living Resource Centre network.

Due to the strength of the business case, the federal government responded very positively and signalled that they were willing to invest in CAILC's infrastructure and capacity as well as supporting one new centre each year. The government at the time was very interested in "building the social economy." CAILC's business plan was seen by government as a good fit with that agenda. Because of this enhanced partnership, CAILC received funding from the federal government for two important initiatives, both designed to enhance the capacity of CAILC and its network of centres. One federal official commented, “If these two initiatives are successful, CAILC will be contributing to the social economy in a significant manner.”

The two initiatives designed to build capacity are the Independent Living Impact Project and the Fund Development project. In many ways, both initiatives support the national association and its network to move to the next level of their development. As the national proposal states, “In parallel, these two investments will enable CAILC and its network to manage its growth, improve accountability and professionalism, fully implement the CAILC accreditation process, provide more services and supports to Canadians with disabilities, increase our sustainability, and markedly improve our diversification of funding for both the national office and the network of ILRCs.”

The *IL Impact Project* ran from 2004 to late 2007. It had three purposes. First, it was designed to create and implement an IL-based national information system that provides reliable information and data on the centres and the consumers who use them. CAILC has worked extensively with its centres to develop common indicators for data collection and a web-based system for actual information gathering. This national information system will ultimately enable CAILC and centres to portray their role in vivid detail. This will illustrate the various ways that Canadians with disabilities use Independent Living Resource Centres and the impact ILRCs have on their lives. This information system is helping CAILC and its network to become a well-documented national enterprise. Table 46 describes some of the processes involved in the development of the national information system. Appendix B lists some of the indicators that were used as the basis of the national information collection system that was created.

Table 46
Thinking Nationally, Acting Locally: The Challenge of National Information Systems

Like all CAILC initiatives, the IL Impact Project included member centres at every step of the project process. The development of the National Database and Information Collection System took its initial direction directly from the CAILC business case of 2004. A national advisory committee was created, whose goal was to support project staff by providing insight, input, and feedback. Regular communication and dialogue would help shape the implementation of this initiative. This advisory committee was composed of representatives from across the Independent Living network, many of whom had experience with technology or information gathering, all of them with an in-depth understanding of their community. This helped ensure that this initiative remained grounded in the experience of consumers while being well connected to centres.

An initial IL Impact Project think tank was convened to define the needs and expectations of centres in the development of this project. This dialogue and planning process was so successful that it is now common practice in national initiatives to provide direction and buy-in from centres by using a think tank or forum approach.

During the development and implementation of the national information system, the involvement of the advisory committee and the centres was critical to the project. The diverse needs of the centres had to be addressed. It was only through consultation and ongoing support that the goals would be realized. To stay true to the Independent Living philosophy, people connected with the project realized early on that the information system would not track individual consumers but would be designed to demonstrate the impact of the network centres at various levels (the individual, the community, and Canadian society).

One of the first challenges was finding indicators that accurately reflect the work being done. How do you capture the work of a national movement in a few statistics? The solution slowly emerged through dialogue and problem solving that the key was to create indicators that demonstrated work done at these various levels. It was also understood that to depict the work that was being done, the information system had to incorporate both quantitative and qualitative aspects. The journey of an individual or the ongoing development of a partnership could not simply be captured numerically.

Many of the Independent Living Resource Centres have collected information on their programs and services for years. One of the issues that became apparent in the development of the CAILC business case was that each centre was collecting these statistics in very different ways. Some centres were tracking number of contacts, while other centres were counting the number of consumers, while still others were showing a breakdown by percentage of time spent in the core program areas. This diversity was like comparing apples to oranges, and did not allow for an accurate picture of the work being done. This patchwork approach illustrated the need for the creation of a system with standardized reporting that enabled better representation of local and national issues. Defining the indicators was a very important step in the process of system development. Again, the involvement of the member centres was key as this took shape. The suggestions provided gave the foundation to the result of indicators and information gathering.

The system that was created provides a tool that strengthens CAILC's infrastructure and increases their creditability with funders on many levels. "The vault," as it became known, had to be user-friendly and adaptable to the needs of individual centres, which now have a strong sense of ownership. Several centres have become champions of the importance of gathering information in ways that can provide effective feedback for centres, CAILC, the movement, and funders.

Second, the IL Impact Project was designed to improve the standards and approaches to core programs by creating principles, strategies, and standards for planning and implementation. CAILC and the Thunder Bay Independent Living Resource Centre took the lead on this project. Tools and resources that had been created by individual centres were collected and a searchable online database was created to develop connections between centres.

Thunder Bay also worked with other centres across the country to develop the principles and strategies to guide core programs. Wendy Savoy, executive director at the Thunder Bay Centre, played a key role in this project. "Having principles and standards," says Savoy, "will bring consistency across the country. For a few centres, it will give people a much needed template and clear expectations." This work involved gathering documentation and synthesizing it to provide a strong base for core programs. This work evolved from human interest stories about core programs and their role in the empowerment and inclusion of citizens with disabilities. Christine Malone, IL Impact Project manager, says that, "Staying grounded in stories ensures that the work will stay true to the IL philosophy." Appendix C presents a summary of this resource material.

Third, the IL Impact Project was designed to enable the national association to develop and publish this book on the history and impact of Independent Living in Canada.

The Awareness, Marketing, and Fund Development Initiative began in 2006. It was designed with three objectives in mind:

- To heighten public awareness of CAILC and Independent Living Resource Centres locally, provincially, and nationally;
- To market CAILC and its networks of ILRCs to large corporations, service clubs, unions, small businesses and foundations to achieve greater funding diversification and financial stability; and
- To use the heightened awareness and professional branding of CAILC as a springboard to raise funds for immediate and long-term proactive growth and financial needs of the association.

With this national initiative, CAILC and its network went through a marketing process that led to a new logo and branding. After sustained dialogue and debate, the national board selected the new logo and the slogan "Independent Living—Promoting a New Perspective on Disability." Based on the new logo and slogan, CAILC then developed a twice-yearly corporate newsletter and a larger, national public awareness campaign designed to attract several corporate sponsorships. The initial success of this initiative saw CAILC develop partnerships with four separate Canadian banks: CIBC, TD, Scotia Bank, and Royal Bank of Canada. In-kind donations also increased, including the donation of 600 phones from Rogers, which were distributed to the centres, who in turn provided the phones to consumers at their discretion.

This Awareness, Marketing, and Fund Development Initiative also enabled CAILC to hire a resource developer, who supports CAILC and its network to build their fundraising capacities. For many centres, this was the first time they had focused on fund development. Linda McGreevy, CAILC's director of resource development, describes some of the benefits for centres: "The ILRCs have made great strides with the support they received from CAILC to increase their fundraising and marketing skills. They have all benefited from workshops on various fundraising techniques, as well as a complete template binder and quarterly communiqué highlighting various fundraising and marketing strategies."

Table 47

Independent Living
Vie autonome

Canadian Association of Independent Living Centres
Promoting a new perspective on disability
Association canadienne des centres de vie autonome
Voir au-delà du handicap

The Independent Living Resource Centres made great strides in moving ahead with marketing and fund development. Many of the centres focused on developing small-business campaigns, the organization of which was based on recruiting high profile community leaders to assist in fundraising. Linda McGreevy points out that, “This not only raises money through small businesses but builds awareness in the community of the existence of the ILRCs.”

One of the major hurdles to implementing this initiative involved changing attitudes towards fundraising. Most of the centres had not been involved in fundraising and did not see that as their role. Their primary business is delivering programs and services to people with disabilities. Linda McGreevy says, “It is interesting to have seen the shift by the majority of the centres who now see the benefits to fundraising and marketing their organizations.” McGreevy adds that one of the driving forces of this initiative is the realization of the value of building a sustainable and diverse funding base. While CAILC and its network of centres all agree that the government should continue to provide funding to support Canadians with disabilities, there is growing recognition that a broader funding base will create more opportunities for the centres and citizens with disabilities.

In addition to these two substantive initiatives, IL Impact and Fund Development, over the years CAILC has developed other resources to assist centres in building their capacity. These resources have assisted centres in being effective both internally and externally, and include resources on board development, strategic planning, and citizen engagement.

Summary and Reflections

National initiatives have had two major influences on the Independent Living movement. First, they have *strengthened the internal work* of the national association and the network of centres. In recent years, this strengthening has been very timely, since some centres have struggled with both leadership and finances. The two capacity building initiatives, IL Impact and Fund Development, helped centres bring focus to their core programs. These two initiatives, with their process and products, are enabling CAILC and its network to deepen the common ground that they share. Centres now work from an agreed-upon set of principles, gather similar information about their consumers, use a well-understood process for ongoing accreditation, and share strategies on fundraising. While local issues and systemic barriers continue to plague some centres, these national capacity-building initiatives have contributed immensely to the Independent Living movement.

Second, national projects have *strengthened the external work* of the national association and the Independent Living Resource Centres. National initiatives that address significant issues facing people with disabilities have enabled the Independent Living movement to use its wisdom and experience to involve others in the needed resolution of these challenging issues. In some respects, this partnership work in family violence, crime prevention, literacy, access to recovery, and healthy lifestyles is social justice work. Independent Living leaders are working collaboratively with educators, recreation professionals, the police, and rehabilitation professionals to create contexts, environments, and organizations that understand and include people with disabilities. We know from these projects that inclusion is often a challenge for established professions, especially if laws and procedures need to be changed to make social justice a reality.

National projects that collaborate with other national and local partners have created a ripple effect that goes well beyond the Independent Living movement. Resource materials, websites, educated professionals, and new partnerships are four strong legacies of all projects. In addition, other outcomes vary from project to project, but include other like-minded national groups taking on disability issues, the federal government reviewing legislation, and non-disability organizations calling on CAILC for consultation advice.

At the same time, the reality is that the national association has not had the resources to do intensive follow-up work with each of these projects. As one leader said, "If we had the resources, we would need to do more intentional work to embed these new paradigm ideas into the fabric of mainstream organizations." Table 48 summarizes the insights gained from these national initiatives.

Table 48
National Independent Living Initiatives:
Their Contribution to Change

1. CAILC has sponsored two types of national initiatives over the years. One type involves national and local partners coming together with CAILC and its network to work on an identified issue. The second type of national initiative is designed to build capacity of local centres, and involves ILRCs working closely with CAILC.
2. In 2004, CAILC extended its partnership agreement with the federal government. CAILC's business case identified some new directions and support for enhanced leadership and capacity building of CAILC and its network. This expanded partnership between CAILC and the Government of Canada included funding for an IL Impact Project and a Fund Development Project. These projects contributed significantly to building the capacity of CAILC and ILRCs to be more effective and sustaining, as well as funding three more centres.
3. Over the years, CAILC has sponsored several national initiatives designed to resolve issues that face Canadians with disabilities. With several national and local non-disability partners, these projects have helped move disability issues into the mainstream. The ripple effects from these initiatives have included useful resource materials, websites, educated professionals, and new partnerships. Leaders agree that more resources for follow-up would create deeper change with mainstream organizations.
4. With sustained capacity for the future, the Independent Living movement faces many more challenges that require national initiatives, sustained

funding, and sound leadership. Other issues that can be addressed include reducing the social isolation of people with disabilities and reducing the poverty of Canadians with disabilities. Like previous national initiatives, these kinds of issues will require collaboration with other sectors of society.

It is interesting to reflect on the national initiatives and the influence they may have for the future. After all, the national association and its network have learned how to collaborate with non-disability partners in some very interesting ways. These kinds of collaborations are becoming vital in a society that is recognizing the need for comprehensive approaches to solving social issues for all members of society. In addition, research shows that in the last few decades many organizations have been moving from hierarchical structures to much more collaboration among teams of workers.[2] CAILC's insights into collaboration and inclusion of people with disabilities could be very timely for the learning of other social movements that are working on related social issues.

National initiatives, like social innovation in general, require leadership. In a leadership study on the Independent Living movement completed in 2000, Cathy La France, a leader from British Columbia, recommended that CAILC strengthen its ability to respond to and influence social and political change in Canada.[3] The last few years have seen CAILC respond to this challenge. The national initiatives have been instrumental in this journey toward enhanced leadership and capacity building. In the future, we can anticipate that many other issues might be pursued through national initiatives, including reducing poverty or reducing loneliness of people with disabilities.

> *We should never, never be afraid or ashamed about dreams. The dreams won't always come true; we won't always make it; but where there is no vision, a people perish. Where people have no dreams and no hopes and aspirations, life becomes dull and a meaningless wilderness.*
>
> — Tommy Douglas, Premier of Saskatchewan, 1944–1961

Endnotes

1 See [www.vibrantcommunities.ca].

2 Robert Florida, *The Rise of the Creative Class* (New York: Basic Books, 2004).

3 Cathy La France, *Passion, Professionalism, and Politics*, A Workshop for the Canadian Association of Independent Living Centres. Ottawa: CAILC, 2000.

Chapter 11

Expanding Interest in Independent Living: United Nations Day and Its Influence

The United Nations has had a long-standing interest in human rights. In 1948, shortly after the founding of the UN, a Universal Declaration of Human Rights was proclaimed by the General Assembly. What is most interesting about this Declaration is the focus on rights for everyone. Former secretary-general of the UN, Kofi Annan, has said, "The United Nations, whose membership comprises almost all the states in the world, is founded on the principle of the equal worth of every human being."

Some of the articles in the UN Declaration give a strong sense of this commitment:

- All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood;
- Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status;
- Everyone has the right to life, liberty, and security of person;

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

These UN principles created an international framework for all citizens to experience human rights and inclusion. To its credit, the UN has painstakingly defined a broad range of internationally accepted rights—including economic, social, and cultural, as well as political and civil rights. In addition, it has established mechanisms with which to promote and protect these rights and to assist governments in carrying out their responsibilities.

Despite this progress, the reality 60 years after the UN Declaration is that many citizens continue to be denied their human rights, including the full participation of citizenship. The UN became aware of this gap in the 1970s and began to promote the rights of specific populations. In 1982, the World Programme of Action Concerning Disabled Persons was adopted by the General Assembly. Included were goals of full and equal enjoyment of rights and participation in society by persons with disabilities. This Declaration was further supported in 1983 by the UN Decade of Disabled Persons, designed to encourage governments to work with the disability community to address human rights and participation issues facing people with disabilities.

International Day of Disabled Persons

In 1999, the United Nations declared December 3 as the annual International Day of Disabled Persons. This UN Day was designed to increase awareness of the potential of citizens with disabilities. The UN suggested four ways that countries could respond to the International Day:

- Involve a range of governmental and non-governmental organizations;
- Organize events and forums for educational purposes;
- Celebrate the contributions of persons with disabilities; and
- Take action to improve people's lives.

In 2001, the marketing committee of the Canadian Association of Independent Living Centres (CAILC) was considering declaring an Independent Living Day. They then struck upon the idea of building on the UN International Day of Disabled Persons. Although the UN Day was almost unknown in Canada, the committee was excited that this day could become a catalyst for informing both politicians and citizens about Independent Living and related disability issues.

Once a commitment was made to hold UN Day in Canada, the CAILC committee struggled with a message that could guide the day. Traci Walters remembers how the committee came up with the Black and White campaign. "It was difficult trying to come up with a campaign message," says Walters. "Then someone, in frustration, said, 'It's simple, it's black and white, people with disabilities can contribute to society if given opportunities.'" CAILC also decided, if they could organize the UN Day, they would keep it positive and focus on the vision, partnerships, and what remains to be done so that people with disabilities can be full citizens.

CAILC wrote to Prime Minister Jean Chrétien and asked him to make a formal request to the UN to select Independent Living as the theme. In the spring of 2002, the Prime Minister wrote to Kofi Annan, Secretary General of the United Nations, requesting that the UN Day later that year reflect the theme of Independent Living. Mr. Annan agreed and the 2002 International Day was given the Canadian-led theme, *Independent Living and Sustainable Livelihoods*.

CAILC initially saw the UN Day as a chance to work with its local centres and the federal government to broaden the education and awareness of Independent Living. Traci Walters, national director of CAILC, wrote to the centres and to all members of parliament in the fall of 2002:

> We are very excited that this Canadian-led initiative on December 3 will heighten awareness of the needs of 600 million people with disabilities throughout the world, and this underlines the importance behind the philosophy of Independent Living as a means to develop sustainable lives.
>
> As stated in the UN website, "Persons with disabilities should be beneficiaries and decision makers in social life and development; this goal places an emphasis on individual and innovative choices and participation

> of persons with disabilities in their personal and community life. By focusing on unique talents of individuals in the universal movement by, for, and with persons with disabilities to promote independent living and sustainable livelihoods, and by recognizing the right of persons with disabilities to self-support, decent work, dignity, respect, self-reliance, and self-determination, communities around the world will be able to develop new ideas and options for a strengthened basis for its economic, social, and cultural advancement as a whole.

In the six-month lead-up to the first UN Day in Canada, the national association provided monthly communiqués to the centres. Table 49 presents the CAILC advertisement for UN Day 2002, emphasizing the Black and White message and the theme that was sponsored by Canada and the UN.

Table 49

The first UN Day co-sponsored by CAILC and the federal government was a rousing success. Peter Milliken, speaker of the House of Commons, hosted a reception with CAILC, and more than 130 people and MPs from every political party attended. During the sitting of the House of Commons, 20 disability leaders were in the gallery. On the floor of the Commons, Jane Stewart, Minister of Human Resources Development Canada, announced UN Day and recognized the leaders in the gallery. A morning breakfast and press conference included statements by Jane Stewart and David Kilgour, Secretary of State. Minister Stewart confirmed the

Government of Canada's commitment to work closely with the national association to ensure that "Canadians with disabilities can contribute more fully to the economic, social, and cultural life of the country." At this event, the federal government also released *Advancing the Inclusion of Persons with Disabilities: A Government of Canada Report*. This report was the first progress report on how the federal government was doing in relation to disability issues.

During the morning event, high-tech entrepreneur and commentator David Chalk, who himself has a disability, spoke about the potential of including citizens with disabilities in the fabric of Canadian society. "There are many people in Canada, capable and waiting to become active members in the workplace and society, given the opportunity," said Chalk, founder of the highly successful Chalk Media. Furthermore, he noted, "With government, business, and the community working together to provide the right resources, individuals with disabilities will be able to maximize their potential and inevitably help our society to prosper."

UN Day, 2007.
Above: Steve Estey and TraciWalters with sign language interpreters
Below: Paul-Claude Bérubé presenting a plaque to the Honourable Peter MacKay for the support of the UN convention on the Rights of Persons with Disabilities

CAILC highlighted 15 "Untold Stories" as part of its first UN Day. Each story included a black and white photograph and a short vignette about a Canadian with a disability. To demonstrate the spirit of the first UN Day, we share two of the stories in Table 50. Most centres also shared their own untold stories with their media. Several media outlets highlighted the UN Day with stories and facts about Canadians with disabilities.

Table 50
Untold Stories—From 2002 UN Day

André Robichaud: Never Give Up

Although André was born with renal disease and undergoes dialysis during the night, that hasn't stopped him from pursuing his goals.

André is determined to remain independent and active in spite of the hurdles in his way. Even while in dialysis, he kept on studying and finished high school. Thanks to a first successful transplant, he experienced what it was like to be full of energy for the first time in his life. He was able to complete his post-secondary studies and then found a full-time job in a Community Access Centre.

What are his plans for the future? André wants to study computer science and build a career for himself in that field. André says the services and support he received from an Independent Living Centre in Shippagan, New Brunswick, really enabled him to sustain his desire to remain independent.

Lucie Lemieux-Brassard: Committed Advocate

In 1991, after an accident, Lucie Lemieux-Brassard's life took a sharp turn. She became a wheelchair user and had to quit her job because there was no elevator to her second-storey office. Despite the challenges, Lucie didn't give up. Instead, she battled her depression, and rose to new heights as a committed defender of the rights of persons with disabilities.

Lucie lives in Montreal with her husband and son. Since her accident, many doctors have told her that she faces too many challenges to raise a family properly. She consistently proves them wrong, demonstrating that people with disabilities can be full and active members of the community.

Lucie's belief in the full citizenship of people with disabilities led her to enrol in law school. She has committed to use her skills as a lawyer to advance the rights of Canadians with disabilities. In particular, Lucie has become very active in numerous provincial and national disability organizations. Lucie is connected with the Montreal Metropolitan Independent Resource Centre.

New Connections, New Partners: UN Day Builds Momentum

The UN Day has been a catalyst for expanding interest in the Independent Living movement. At the federal level, each successive UN Day has included an array of new connections and partnerships. More and more private and public partners have come on board with support for the event, both as co-sponsors and/or with the provision of resources. The federal government has continued to support the December 3 event and politicians participate in the event each year. Table 51 outlines the themes of the UN Days.

Table 51
Themes of International Day of Disabled Persons, December 3
Sponsored by the United Nations

2007	Our Place in the World: An International Perspective on Independent Living, Disability Rights, and Inclusion
2006	E-Accessibility
2005	Rights of Persons with Disabilities: Action in Development
2004	Nothing About Us Without Us
2003	A Voice of Our Own
2002	Independent Living and Sustainable Livelihoods
2001	Full Participation and Equality: The Call for New Approaches to Assess Progress and Evaluate Outcomes
2000	Making Information Technologies Work for All
1999	Accessibility for All for the New Millennium

As importantly, local Independent Living Resource Centres have been mobilized by this event. Beginning with the first UN Day, many centres have created parallel events in their home communities. In 2002, the South Saskatchewan Centre in Regina, for example, created a two-hour event that included presentations and a community forum for consumers and other citizens. The forum was attended by almost 100 people, where the disability community presented recommendations from a Disability Action Plan to the government of Saskatchewan.

During the first UN Day, CAILC created a proclamation template for centres to take to their local politicians. Several mayors and city councils across the country recognized Independent Living and declared December 3 UN Day in their communities.

In subsequent years, more centres have become involved in parallel events. The 2003 event featured a movie, *Bearing Witness,* made about Luc Melchior from the Victoria Disability Resource Centre, member of CAILC. Many of the centres sponsored public events where they screened the film, and followed it with discussions. In Ottawa, the National Film Board was a major sponsor of the event, which included a reception, film showing, and a question and answer period (including live questions via the webcast from around the world) with Luc Melchior and the filmmaker Dan Curtis.

Over the years, the number of consumers, government officials, mainstream services, national non-governmental organizations, and politicians in attendance at UN Day events has been increasing. One leader noted that this was seen by some as “a way for people to feel a sense of disability pride.”

By 2004, thirteen other national disability organizations were partnering with CAILC to co-sponsor the UN Day. Groups included Council of Canadians with Disabilities, Canadian Association of Community Living, and the Canadian Paraplegic Association. This was a powerful display of solidarity within the disability movement in Canada. Traci Walters, national director of CAILC, describes the partnership of the national organizations as “an excellent example of group cohesion in the disability movement.” Keynote speakers included Minister Ken Dryden, and a standing-room-only crowd of over 200 people attended the Ottawa event.

The 2004 UN Day also included a partnership with Famous Players and Cineplex Galaxy. The theatre chains announced a policy of “Access Entertainment” cards for free admission for support persons for people with disabilities who needed to be accompanied to movies. At the national event, the Ontario government outlined its plan to implement legislation entitled Accessibility for Ontarians with Disabilities Act. It was fitting that the theme of the 2004 UN Day was "Nothing About Us Without Us."

In 2005, the theme was "Rights of Persons with Disabilities: Action in Development." Most centres across Canada sponsored a local event and encouraged members to listen into the webcast of the national event. The CAILC webcast had more than 18,000 hits that year! In CAILC's summary of the 2005 UN Day, it was noted that, "The International Day of Disabled Persons celebration grows with each passing year. CAILC will continue to lead Canadians with disabilities and the national community in celebrating our diversity, ability, and achievements and to raise awareness of disability and disability issues in Canada on this day."

In November of 2007, CAILC's national conference on Independent Living convened in Ottawa, the nation's capital. The day before the conference began, a full-day event called End Exclusion was held. Co-sponsored by CAILC, the Council of Canadians with Disabilities, and the Canadian Association for Community Living, this annual event brought together a wide range of disability advocates and activists. At the end of a stimulating day of sharing how to end exclusion, a UN Day celebration was held. This year was particularly significant because disability leaders and the federal government could congratulate themselves that Canada had signed the UN Convention of the Rights of Persons with Disabilities earlier that year.

Summary and Reflection

It is always difficult to assess the impact of a single event such as the UN Day. However, some key trends point to the influence of CAILC's sponsorship of UN Day on disability issues in Canada.

First and foremost, the participation and support of the federal government for this yearly event means that the UN Day has become part of the landscape in Ottawa. It has become more difficult for political parties to ignore disability issues.

Second, with its powerful themes each year, the UN Day creates awareness of new paradigms of disability, rights, and community. Several Independent Living Resource Centres report how much they appreciate CAILC's efforts to organize the event. One executive director notes that, "The UN Day is a catalyst…it creates an opportunity for us to reach out to our local politicians and other leaders in our community."

Third, the UN Day is helping the concepts inherent in Independent Living to move beyond Independent Living Resource Centres. With tens of thousands of hits to webcasts of the yearly event, Independent Living is becoming better known across Canada as a philosophy and framework for citizenship.

Fourth, the UN Day creates momentum for change. Each year, various governments, as well as non-governmental organizations, make announcements on December 3. In many municipalities across Canada, UN Day is now seen as an important event for addressing rights, accommodation, and accessibility.

The partnerships that CAILC has developed with UN Day have paid huge dividends. We know that relationships are central to social change. The UN Day has made it possible for CAILC to deepen its relationships with the disability community, with the private sector, and with the federal government. As one senior government person remarked, "Despite its strong advocacy on disability issues, CAILC has built trust with government."

Finally, keeping the UN Day positive and upbeat has proved to be the secret to attracting "outsiders" from government and the private sector. For a day, these citizens and leaders get to feel the energy and the commitment of the disability movement. By interacting with leaders in the movement, they experience the essence of Independent Living. Over time, many of these corporate and government leaders "get it" and some have become champions of disability rights and inclusion in their own spheres. Table 52 highlights the role of CAILC and the influence of the International Day of Persons with Disabilities.

Table 52
UN Day: CAILC Role and Influence

1. In 1999, the United Nations declared December 3 as the annual International Day of Disabled Persons. The UN Day was designed to increase awareness of the potential of citizens with disabilities.

2. CAILC became involved in the UN Day starting in 2002 and worked with the federal government to co-sponsor a Canadian-led international theme for 2002.
3. Over the years, UN Day has built momentum and has led to numerous new partners for CAILC, within the disability movement, with business and the private sector, and with mainstream national organizations.
4. Increasingly, centres have created local events and have worked to influence local politicians and leaders about disability issues.
5. Among the outcomes of UN Day are: growing awareness of Independent Living; and increased involvement of the federal government and national disability organizations to continue to provide these opportunities for education and collaboration.
6. The UN Day has become integrated into the fabric of the Independent Living movement.

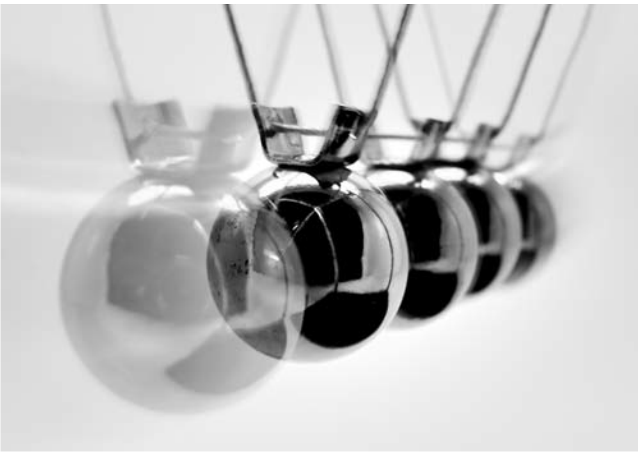
On March 30, 2007, Canada's ambassador to the United Nations signed the United Nations Convention on the Rights of Persons with Disabilities. By the end of 2007, almost 120 countries had signed the Convention, the first comprehensive UN Convention of the 21st Century. As the preamble to the Convention states, "It marks a 'paradigm shift' in the attitudes and approaches to persons with disabilities." The Convention is intended as a human rights instrument, but it has an explicit social development focus. Many of the articles in the Convention relate to community participation and independent living.

During the next two years, the Canadian government will assess their laws and procedures to be sure that they can actually ratify the Convention. This will be a huge task, since it will also involve laws and procedures of the provinces and territories. Some leaders in the disability movement have pointed out that this is a window of opportunity for the disability community to work with the federal and provincial governments to ensure that Canada can ratify this important UN document.

For several years before the landmark signing of this UN Convention, the Council of Canadians with Disabilities (CCD) had been actively promoting the Convention with the federal government. During the last months of 2006, when the federal government appeared to be wavering on whether to sign this Convention, CAILC, CCD, the Canadian Association for Community Living, and Amnesty International led the charge and mobilized almost 50 disability organizations to advocate with the federal government to sign this important international document. This kind of collaboration among the disability community is an example of the impact that CAILC and the rest of the disability community can have when they work from a common vision and clear strategic directions.

> *Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.*
>
> —Margaret Mead

PART III



KEY ISSUES IN BUILDING TOMORROW

Part III addresses some of the key issues identified by leaders in Independent Living that are likely to influence the future of the Independent Living movement. The leaders suggest ways that the movement needs to address these issues.

Chapter 12

Addressing Oppression: The Struggle for Diversity and Inclusion

The history of disability can be considered a narrative about oppression. Too many Canadians with disabilities have lived with stigma and segregation. Others have experienced the cruelty and wounds of poverty and abuse. Several social movements in Canada are working to reduce oppression and end systems that dominate and control people with disabilities. The mental health movement, the community living movement, and the Independent Living movement are all working toward social inclusion and full citizenship for every person with a disability.

Leaders admit it has been a struggle to address oppression as experienced by people with disabilities. We can think of oppression and discrimination as issues that can touch every aspect of people's lives. Whether this oppression is because of disability, gender, class, or race, it is often direct and demoralizing. It can also be more subtle and be reflected in ways that we may not immediately recognize. Many people with disabilities, for example, report that it is not unusual for people to talk down to them.

There is often a connection among these dimensions of oppression. Women with disabilities, for example, are much more likely to be poor and marginalized than men.

Most frameworks that address ableism, sexism, classism, and racism suggest that we need constantly to name the oppression, take it apart, or deconstruct it. A similar framework is used within the Independent Living movement. This will be further explored in this chapter. People who work on issues of oppression also note how important it is to be aware of its various forms and processes, and identify strategies for addressing them.

The Devaluing of Difference: From Naming to Awareness

Several people we talked with remember the early years of the Independent Living movement as a period dominated by white, middle-class men. Cathy La France, an Independent Living leader from British Columbia, acknowledges that, "These leaders who we refer to as the pioneers of the Independent Living movement have accomplished great things for the movement and have been recognized nationally and internationally for their work, and rightfully so." She adds, however, that, "Likewise, there are many women who have provided strong leadership in the movement, but they seem to provide a different style of leadership and, unfortunately, do not always get acknowledged or recognized for the work they do."

Another female leader says, "Women's issues were simply not part of the movement in the early years. Men were the leaders and it was very goal oriented." Similarly, in the early years, issues of race, culture, and ethnicity were not prevalent in the dialogue about Independent Living and the impact it might have. As Canada has become increasingly diverse, the Independent Living movement has become more aware of how these issues need to reflect the way centres work with a wide range of Canadians. Issues of gender, class, and race influence the work that centres do in many ways, some of which include language, participation, decision making, and ways of working with consumers.

It is not surprising that the Independent Living movement in recent years has embraced the struggles of women and racial minorities. These issues must be seen in terms of hegemony. Simply put, hegemony refers to the dominant historical way of thinking and acting. The Western world was constructed on patriarchal assumptions. Systems of medicine, law, and political authority flowed from assumptions that historically saw women, people with disabilities, and other minorities as less than full citizens. These assumptions have affected Canadians in a wide range of spheres. As examples, women in Canada have had the vote for less than a century, and many Canadians with disabilities still do not have full access to public education or to the disability supports they require.

Patricia Pardo, former executive director of the Calgary Independent Living Resource Centre, has written about the challenges faced by women with disabilities. She describes how women with a disability encounter discrimination that "restricts their options and opportunities for equal participation in economic, social, and political life of society."[1] Women with disabilities face what some have called "double jeopardy," experiencing oppression because of their status as women *and* as persons with a disability. Canadian statistics confirm what Pardo describes as the "limitations" placed on women as daughters, wives, and mothers. Women with disabilities earn far less that men with disabilities, and participate in the labour force at a rate of 37.5 percent (compared with a 45 percent rate for men), while non-disabled women participate at a rate of 67.9 percent. In addition, 86 percent of women with disabilities surveyed as part of a Winnipeg study reported they had experienced abuse in their lives.

The oppression experienced by people with disabilities is diverse. Poverty is very common among women and men with disabilities. Many people with disabilities live on disability pensions, with incomes well below the poverty line. Poverty is a direct result of limited educational opportunities, as well as conditions that limit the employment of people with disabilities. Limited resources make it difficult for women with disabilities to move beyond oppression.

Mary Reid, former executive director of the St. John's Centre, says that these issues of oppression are further perpetuated by the fact that neither the women's movement nor the disability movement has fully embraced the serious barriers to equality that exist for women with disabilities. Certainly, government policies have not reflected the need to address issues of inequality.

The naming of oppression can be very unsettling. People with power or status often feel quite challenged when "outsiders" name the way that difference is negatively valued. In part, this discomfort results from the privilege and advantage that the dominant group is hesitant to give up. It can also result from the limited experience that dominant groups have in considering the views of minorities. Yet, naming discrimination and oppression—and how difference is often negatively valued—is an important part of the process of change and empowerment.

Some people in the Independent Living movement feel that naming the issues that women and other minorities face has gained momentum in recent years. Others express concern there has not been enough intentional dialogue about these issues. Some leaders note that *how* we name differences can be key to whether dialogue can follow. When naming occurs in anger, it often leads to defensiveness on the part of the other party. One leader notes that when women have raised issues in the Independent Living movement, they have often been responded to with respect. She adds, "One key has been to raise gender and race issues in a peaceful, non-blaming way." People making this argument believe in forceful advocacy, but argue that it is most effective when it leads to dialogue and action.


Cecelia Carroll

The metaphor of *voice* has been significant as women and other minorities with disabilities have begun to speak out. Cecelia Carroll, a board member at the St. John's Independent Living Resource Centre for the last 20 years, says that women have always brought commitment and passion to the movement. She says that these qualities have been essential to counter the tendency of some men in the movement who want to tell people what to do.

In terms of women countering these cultural tendencies, Cathy La France says that women as leaders must address these issues head-on. "Unless the Independent Living principles are deeply embedded in the centres," says La France, "women can end up perpetuating and imitating the traditional top-down style of leadership/management just because it is so embedded within our systems." There is always the risk that women and other minorities will internalize the oppression they are experiencing.

In 1987, the formation of the DisAbled Women's Network (DAWN) raised the profile of the rights of women with disabilities in Canada. Irene Feika, former chair of the Council of Canadians with Disabilities, has written that, since the founding of DAWN, "The concept of women with disabilities becoming part of the overall women's movement has had long-term significance around the world."[2]

In turn, this growing awareness of the rights of minorities has enabled the Independent Living movement to benefit from the leadership abilities of numerous women with disabilities. Their invaluable contributions will continue to strengthen the movement for all people with disabilities.

The Valued Role of Women in Independent Living

Women as Leaders

Women represent over 80 percent of workers in the non-profit "caring" sector (health, education, and social services).[3] Women have played significant leadership roles in the Independent Living movement since its inception. Since the 1990s, women's participation has helped broaden the scope of the movement. Female leaders have provided role models for younger women with disabilities, and women's ways of working have tended to be highly collaborative.

Sandra Carpenter from the Centre for Independent Living Toronto says the movement needs to be clear about its role and goals and not emulate able-bodied values. Carpenter argues that centres should serve as a "counterpoint" to everything else going on in the culture related to disability. Cathy La France worries that women can fall into the role of "taking care of others," which conflicts with the Independent Living approach.

The comments of these women leaders indicate how important it is to be vigilant in the pursuit of human rights and social inclusion. The principles of Independent Living promote the understanding that all human beings are of equal value. The experience of centres reflects that wiser decisions are made when women and men actively participate in their resolution. Centre leaders also know

Lois Miller, Mary Reid, Cathy Horne, and Cecelia Carroll (centre, front)

that when they replicate hierarchical management, it favours men and able-bodied leaders. These women argue that the Independent Living movement must continue to be attentive to issues related to gender to insure that this knowledge becomes part of the everyday life of every centre.

Women have been influential in providing leadership and in being role models for other women. To illustrate this theme, Table 53 highlights the roles played by eight women leaders from across Canada.

Table 53
Women as Leaders in the Independent Living Movement

Mary Reid

Mary Reid was the first executive director of the St. John's Independent Living Resource Centre and played a major role in the centre's development. Mary describes herself as a person who values and believes in people. She knows and trusts that people have their own solutions, and believes in supporting what is already in the community. Mary built relationships and contributed significantly to the changing mindset toward disability in Newfoundland and Labrador. She was a significant catalyst for change in the province and was totally dedicated to Independent Living. Mary understood the importance of building capacity and was able to convince the provincial government to fund and support the St. John's Centre. Mary Reid brought this same passion and commitment to the Canadian Association, where she made major contributions to policy development.

Traci Walters

Traci Walters became national director of the Canadian Association of Independent Living Centres in 1993 and has had a major impact on the movement.

As a former leader at the Niagara Centre for Independent Living, Traci understands the issues facing people in the national grassroots movement. During her tenure, CAILC has expanded from being an administrative arm of the centres to providing strong leadership across a number of areas. Traci has built positive relationships with government, played a major role in expanding the capacity of the national association, and helped build a movement that has wide credibility across the country and internationally. Traci leads with her heart and mind and is renowned for being able to see the big picture of what the movement is and what it can become. Traci Walters is a mentor and role model for many women with disabilities.

Carole Sénéchal

Carole Sénéchal was a founding member the ILRC *Région du Bas-Saint-Laurent*, Trois-Pistoles, the first Independent Living Resource Centre in the province of Quebec. In 1987, Carole became the centre's first chair of the board of directors and was in that leadership role for 15 years. She has played a major role in educating other agencies in Quebec about the philosophy and strengths of an Independent Living approach. Carole believes deeply in the core programs of centres. At the ILRC, Carole and her colleagues developed very effective information and networking approaches. She has also been part of a centre that has provided leadership in research within the Independent Living movement. Her passion and dedication have been obvious to anyone who has worked with Carole.

Sandra Carpenter

Sandra Carpenter has played numerous leadership roles in the Independent Living movement. Currently Sandra works for the Centre for Independent Living in Toronto. Previously, she was manager of the Centre for Disability and Work with the Ontario Ministry of Labour, and senior manager for disability issues in the Ontario Ministry of Citizenship, where she was able to bring the Independent Living philosophy into the world of work for people with disabilities. Sandra was one of the leaders in the Attendant Consumer Action Coalition in Ontario and was the director of the Canadian Independent Living Foundation. In all these roles, Sandra brought energy, enthusiasm, and most of all, a deep commitment and understanding of the values of Independent Living. Over the years, Sandra has also contributed much to the movement through her insightful writing about Independent Living.

Paula Saunders

Paula Saunders has been a leader with the Independent Living Centre of Waterloo Region for the last 20 years. During this time, she has demonstrated confidence and skills related to individual advocacy, peer support, and community development. Her work with the Region of Waterloo and the cities of Kitchener and Waterloo related to accessible design has been very influential. Paula has spearheaded numerous partnerships designed to enhance the lives of people with disabilities. Paula was a CAILC board member for 12 years, and contributed immensely in that role. Paula is held in high esteem by other leaders because of her integrity, passion, and knowledge.

Tracy Knutson

Tracy Knutson was the executive director of the South Saskatchewan Independent Living Centre (SSILC) for 12 years. In this role, Tracy initiated several community development projects and created an innovative approach for supporting individuals to build their personal capacities. She has always been deeply committed to inclusion and was very influential on the City of Regina's Advisory Committee on Access. Tracy recently completed work as the Inclusion and Aboriginal Services Coordinator for the City of Regina, where she moved the Independent Living philosophy into the mainstream. As a CAILC board member, Tracy brings the same commitment to inclusion and justice to that decision-making table.

Frances Clark

Frances Clark was a founding board member of the Richmond Disability Resource Centre. As a former small business owner and a city councillor in Richmond for years, Frances used her networks and connections to help create an Independent Living Resource Centre that is deeply embedded in the community. Because of her leadership, the Richmond City Council was the first city in Canada to contribute ongoing funds to a centre. Frances' energy and commitment to Independent Living is contagious and she has become a leading spokesperson for the movement in British Columbia. Frances' gift for building relationships has also enabled the Richmond Centre to build effective partnerships with foundations. The Richmond Centre today reflects a multicultural approach to Independent Living, thanks to Frances and other leaders in Richmond.

Cathy La France

Cathy La France was the executive director of Cowichan Independent Living in Duncan, British Columbia, for a decade. She was originally led to work in Independent Living because of her dissatisfaction with traditional services for people with disabilities, and she is very aware of the wounds that many people with disabilities experience. As a leader in British Columbia, Cathy brings a new paradigm approach to her research. Her study on leadership within the Independent Living movement in 2000 challenged the movement to address some key leadership issues. Currently involved with the Victoria Centre, Cathy shows in her work the importance of building a movement that is inclusive, gender balanced, and collaborative.

These eight women are wonderful representatives of the Independent Living movement. They bring a strengths approach to their work and they value relationships highly. While, individually, they have each had enormous influence locally and nationally, collectively these women, and many more, have actually contributed significantly to the direction of the movement. This is no longer a movement of star leaders, but has truly become a collaborative enterprise. In many ways, this is one powerful outcome of women's ways of working.[4] Although not all women work differently than men, it can probably be said that the leadership of women in this movement has led to networking and capacity building as central features in the way CAILC and its member centres now work.

Cecelia Carroll, national board member from St. John's, says, "Women bring celebration and hospitality to their work." In many ways, hospitality expresses one of the most powerful ways that women contribute. While hospitality has traditionally involved women behind the scenes, these eight women represent the qualities in their leadership roles. As we have seen, women as leaders have had significant benefits for other women and the movement as a whole.

Women Supporting Each Other

In addition to leadership, many women find mutual support empowering. At the Independent Living Centre in Kitchener–Waterloo, a women's group meets monthly to provide support to each other. This connection involves storytelling, watching and reflecting on a movie together, or listening to a guest speaker on an issue of importance.

A similar group was established in Saskatoon when the women's group DAWNing Saskatoon (a member of DAWN Canada) was re-established in 1998 with the support of the North Saskatchewan Independent Living Centre. As with many of the women and communities mentioned earlier, the development of a hierarchy was discouraged. The goal of peer support was to create a positive space for women to be able to share experiences and have all individuals involved guide the direction of the group. This process enabled all the women to develop their confidence and leadership skills and share this with their larger networks. An example of this is demonstrated with Jane Selby, a DAWNing member, who found her experience so positive that she developed a women's support group within her consumer mental health organization. This exposed many new people to the Independent Living philosophy and created awareness around issues for mental health consumers in the local DAWNing group. In Table 54, Diane Driedger from Winnipeg describes her personal experience with other women in a peer support context.

Table 54
Women Supporting Each Other: Diane Driedger's Story

As a young non-disabled woman in the early 1980s, Diane Driedger worked with Henry Enns and Allan Simpson in helping to launch the Winnipeg Independent Living Resource Centre. At the time, Driedger was working with Disabled Peoples International and later went on to be employed with the Council of Canadians with Disabilities (CCD).

In 1990, Driedger had an opportunity to help start an Independent Living Resource Centre in Port of Spain, Trinidad, through her job with the CCD. Driedger says, "CCD was able to raise seed money to pay for the staff and facilities of the centre. They offered many programs, training for jobs, computers, information and referral, advocacy, and peer support."

At the same time, Driedger started her transition to being a person with a disability. She explains, "In 1991, I started having myofascial pain in my arm and neck from holding the phone at the office (I talked a lot on the phone in those days!). In 1993, I started having strange muscle aches and infections, and indeed, I was sick the whole six weeks I was in Trinidad working at the IL centre."

During this visit, Diane Driedger met Kathleen Guy, a woman with a visual impairment who was "coming out to work" (as they say in Trinidad) to the Independent Living Resource Centre every day. Driedger describes how she worked together with Kathleen on women's programming at the center. "It was Kathleen who said there were no women with disabilities on the other end of the IL lines, and women needed their own peer support. Thus, the DisAbled Women's Network (DAWN Trinidad and Tobago) was born. A peer support and training group arose out of the Independent Living Centre. It was a vibrant, action-oriented group of women, who could really throw the best Christmas parties, as I was to find out in the ensuing years! The movement was never so much fun in Canada, I said to myself. They ran peer support meetings, and training sessions in literacy, crafts, health maintenance, cooking, computer skills, and container gardening."

In 1997, Driedger was recovering from a major bout of fibromyalgia. She says, "The winters of Winnipeg were wearing on my joints and muscles. I knew I needed to experience some heat to get better—my health was depleted. I contacted Kathleen and asked if I could teach some kind of a course at DAWN in Trinidad. I would volunteer, if she could find me a suitable place to live and show me the ropes of living there. I took the funds I had and went to live in Trinidad in October and I stayed until the following April." Diane was asked to teach a self-esteem and body image course once a week at DAWN's office. The students would be 12 years to 80 years old. Driedger thought, "Oh, I have some good things to say about this issue, it will be fun to teach the course. Little did I know that I would be taught so much more about myself than I had ever dreamed."

Driedger sums up her peer group experience: "We laughed, we cried, we commiserated about our lives as women with disabilities. Women who had been coping with disability for a long time had a lot to teach me about the dignity of women with disabilities, and indeed, the dignity of women. I didn't feel like such a freak anymore—the weak bedridden one who couldn't participate in all the activities she used to. I was accepted for what I could give in terms of time and energy. I had come home. Not only did the warm climate improve my health, my self-concept and self-esteem as a woman with a disability was built that year. All of us women were different ages, and had different racial backgrounds and disabilities, but we knew in our hearts that we had something to give and we gave it to each other."

Challenges in Embracing Diversity

Most social movements concerned with social justice call for greater acceptance of diversity. While the acceptance of diversity within Western societies has often meant tolerating difference, the Independent Living movement has worked to embrace difference. The pursuit of this ideal has not been without challenges.

Disability Diversity

The idea of embracing disability diversity has its roots in the cross-disability principle of the Independent Living movement. This principle states that every person with a disability can benefit from the Independent Living philosophy. Yet, when disability leaders say "everyone" or "all means all," a quiet discomfort usually sets in. Society has simply not yet embraced the full citizenship rights of *all* people with disabilities.

Unfortunately, people with complex disabilities are systematically attributed fewer rights and are often seen as being less valuable than other citizens. In many jurisdictions, institutionalization of citizens with complex disabilities is acceptable social policy. In a 2002 poll in Great Britain, 68 percent of people surveyed said they would want an abortion if the baby they were carrying had a disability. These social attitudes, often reinforced by medical practice, make it very challenging for people with disabilities to achieve full citizenship and inclusion.

Allan Simpson, one of the early Independent Living leaders, often challenged the movement about the importance of responding with dignity to people with multiple disabilities. Simpson saw that each person had strengths and gifts and he stressed that it was the job of centres to support everyone in their journeys. Some centres have done significant work in embracing a wide range of people with disabilities and in supporting people with complex needs. Other centres have struggled with their capacity to support everyone who comes through their doors. Embracing diversity has a long way to go, both in society and within the Independent Living movement.

Multicultural Diversity

Another challenge of diversity relates to how centres respond to our multicultural society. In the past two decades, the demographics of Canada have been changing dramatically. In some cities, such as Toronto and Vancouver, various ethnocultural groups make up a large portion of the population. This means that centres must learn how to provide an Independent Living approach for a range of cultural differences. As one leader notes, "This involves becoming aware of our white male history and how that has influenced some of our practices and philosophy."

The Richmond Centre is located in a British Columbia community where the population is made up of a large number of new Canadians from Asia. Recognizing that Canada is a nation of many cultures, the Richmond Centre has been proactive in responding to immigrants and other cultural groups. In a detailed report released in 2005, the Richmond Centre makes a number of suggestions for the development of a multicultural service model.[5]

The first idea is to become knowledgeable about the makeup of your community. In Richmond, for example, 49 percent of the population is Chinese or of other Asian descent. In response to this knowledge, the Richmond Centre includes staff who can communicate in Cantonese, Mandarin, Punjabi, and Vietnamese. Another suggestion is that centres must use day-to-day language that fits with the cultural group with whom they are talking. The Richmond Centre has learned, for example, that the phrase "self-determination" is much more appropriate than "Independent Living" for some cultural groups. These immigrant groups are sometimes threatened by the term Independent Living, which they may take to mean that you are encouraging their family member with a disability to move out of the family home, which might be contradictory to their cultural beliefs.

The goal of the Richmond Centre is to enable staff and volunteers to expand their cultural sensitivity, cultural awareness, and cultural competence. A few other centres have also begun to expand their training and awareness, but most have yet to embark on this important journey. A study completed in 1996 by Patricia Pardo and Debra Tomlinson on multiculturalism and Independent Living also recommended that the movement become more inclusive and responsive to multiculturalism. Along with the Richmond report, this study contains a number of strategies on how to do this.

In term of supporting a culturally competent approach, there are several challenges facing centres and Canadian society in general. For one thing, Statistics Canada has identified “ethnic enclaves” across the country, which refers to geographic areas where one ethnic group makes up more than 30 percent of the population. In 1981, there were just six such enclaves; by 2001, the census data showed there were 254 ethnic enclaves, and the newest census information is likely to show that these enclaves are rapidly expanding across the country. Other research from Statistics Canada shows that some new Canadians are not integrating that well into Canadian society. These insights suggests that social institutions need to address the concerns of individuals within a multicultural society, but also need to work in partnership with others to explore how social inclusion and cohesion can be fostered among all Canadians.

We might say that the challenge is to work across differences and to find common ground. It is important to recognize differences and honour various cultural ways of working. For example, centres are beginning to recognize that immigrant women with disabilities struggle with complex issues when trying to enter the workforce. At the same time, finding common ground enables people to build social inclusion and cohesion. Some centres, for example, have worked with new Canadians to involve them in peer support groups around issues of common concern, such as employment. Other centres have begun to ensure that the multicultural nature of their community is reflected in the makeup of their board of directors.

Bilingualism

The Independent Living movement has another uniquely Canadian aspect of diversity; CAILC is a bilingual organization with six francophone and 22 anglophone centres. There are four francophone centres in the province of Quebec, one in New Brunswick, and one in Ontario. This national network is facilitated through CAILC, which translates all communication across the network. It has sometimes been a challenge for the movement to work across 28 centres in two languages.

At the first official executive director's meeting in 2006, francophone and anglophone leaders met for two days. At the end of the first day, one of the francophone leaders said, "I am surprised how similar the issues are across our two language groups." This common ground will be an important touchstone as the Independent Living movement continues to expand throughout Quebec in the years to come. As an interesting microcosm, the Montreal Metropolitan Independent Living Resource Centre is bilingual, operating in both French and English.

Addressing Poverty

Independent Living Resource Centres tend to reflect the makeup of Canada. Some members are employed and active in their communities. Other members are unemployed and do a lot of volunteer work. The reality is that many members of centres live with limited income or live on a disability pension.

Independent Living Resource Centres all support consumers who are living in poverty. While poverty reduction is not a core focus of centres, some have begun in small ways to look for opportunities to make a difference with this critical issue. It is very challenging for Canadians with disabilities to achieve full citizenship as long as poverty is so prevalent. Some centres in Ontario have worked with a provincial coalition that advocates for increased disability pensions. In 2006, the Ontario government increased the Ontario Disability Support Payments by a very modest 3 percent.

A more promising approach to poverty reduction is occurring in several communities across Canada as part of the Vibrant Communities projects. Vibrant Communities are having success with poverty reduction by engaging a wide range of community organizations, the business community, and government in addressing issues related to poverty. Independent Living Resource Centres in Calgary, Montreal, Niagara, St. John's, Saskatoon, and Waterloo, are within communities that have Vibrant Communities projects. Soon, several other Canadian communities will also have projects. Since people with disabilities remain one of the poorest segments of society, there could be mutual benefits for more collaboration.

Working With Families and Young People

The final diversity issue that some centres have struggled with is the role the Independent Living movement plays with families. Primarily, the mission of centres is with adults with disabilities. Some leaders argue that by connecting more with families who have sons or daughters with a disability, it positions centres to be responsive to children when they become teens. Others are cautious to pursue this path, because family support is recognized as a different set of skills and principles. The other reality is that Independent Living organizations sometimes experience tension with family-driven organizations. This tension happens when family organizations make decisions on behalf of their adult sons and daughters with disabilities, an idea that is quite contrary to the Independent Living approach.

Some centres have created outreach and peer support for teens. The Niagara Centre for Independent Living has found this approach to be especially effective in connecting young people with the Independent Living philosophy. Other centres are recognizing that some of the family movements actually have significant common ground with the Independent Living movement. Both movements believe that new values and principles are needed in order to support empowerment and inclusion. Both are critical of traditional service systems that emphasize compliance. Some centres in Ontario have found benefit to collaborating with family-driven organizations around new paradigm approaches to research and disability supports.

Summary and Reflections

Like most social movements, the Independent Living movement in recent years has had to address issues of gender, class, and race. The fact that these issues have been openly talked about is symbolic of the desire of this movement to be inclusive. While centres strive to support members to be included in the wider community, they also try to be inclusive and responsive to anyone with a disability who requires their support.

On both these counts, most leaders agree that centres can do better. Some of the barriers to full inclusion relate to external conditions that impede participation.

Other challenges relate to limited capacity to reach out to the wider community to address barriers collaboratively. Finally, some centres admit that they themselves have work to do to move to an agenda that fits with full equality within a multicultural society.

Social movements can take some credit for the growing support for diversity that exists in many communities. The Independent Living movement contributes to the mosaic of diversity by pushing for the rights and inclusion of people with disabilities. Research is showing that increased diversity is also being driven by citizens who desire tolerance and new ideas as part of their creative approach to work and lifestyle. Urban research in Canada, for example, shows that young Canadians in particular are very open to gay marriage and other indicators of a society's acceptance of diversity. Participants in Richard Florida's research listed diversity as among the most important factors in their choice of where to live and work.[6] Research on inclusion shows the importance of building the right kinds of supports in order to maximize participation.[7] This kind of research suggests indicators for centres to consider in terms of how they facilitate inclusion and acceptance of diversity in the wider community. Table 55 summarizes some of the ways that the Independent Living movement is addressing diversity and inclusion.

Table 55
The Struggle for Diversity and Inclusion

1. The Independent Living movement has had to address oppression both within the movement and within the larger society. Many people suggest that the movement is making progress in addressing issues of gender, class, and race, but that centres can do better in the future.
2. The naming of oppression has helped centres and their communities increase their awareness of the impact of discrimination and possible community solutions.
3. Women with disabilities struggle with discrimination that restricts their opportunities for equal participation in economic, social, and political life. Despite these barriers, women have provided inspirational leadership within the IL movement, in ways that have influenced the movement itself and the wider community.

4. Independent Living Resource Centres have embraced diversity. Despite this goal, it has been difficult for centres to implement a diversity agenda fully. The lack of full acceptance of disability by society, as well as limited experience by some centres, suggest that the Independent Living movement needs to address gender and multicultural issues in a more systematic fashion.
5. On some of these diversity issues, such as social inclusion or poverty reduction, centres benefit when they participate with others in multi-sector partnerships. Collaboration with others is one of the ways that these systemic issues can be addressed. However, centres may require increased resources to do this effectively.

Living our lives openly and without shame is a revolutionary act.

— Harriet McBride Johnson, *Too Late to Die Young*

Endnotes

1. Patricia Pardo, *From Silence to Song: Voices of Women with a Disability from Around the World* (Ottawa: CAILC, 1998).

2 Irene Feika, "Women with Disabilities: Protected or Controlled?" In *In Pursuit of Equal Participation,* eds. Henry Enns and Aldred Neufeldt (Toronto: Captus Press, 2003), 153.

3 K. McMullen and G. Schellenberg, *Mapping the Non-Profit Sector* (Ottawa: Canadian Policy Research Networks, Series on Human Resources in the Non-Profit Sector, 2002).

4 For further reading on women's ways of working, see Mary Field Belenky, *Women's Ways of Knowing: The Development of Self, Voice, and Mind* (New York: Basic Books, 1997).

5 Frances Clark, Ella Huang, and George Meier, *Multicultural Services and Delivery Model* (Richmond, BC: Disability Resource Centre, 2005).

6 Richard Florida, *The Rise of the Creative Class: How It's Transforming Work, Leisure, Community, and Everyday Life* (New York: Basic Books, 2002).

7 John Lord and Peggy Hutchison, *Pathways to Inclusion: Building a New Story with People and Communities* (Toronto: Captus Press, 2007).

Chapter 13

Standing in the Future: Challenges and Possibilities

Although it is not possible to predict the future, it can be a useful exercise to imagine standing in the future, as King Arthur did in the *Knights of the Round Table*. By anticipating the future, we can better prepare ourselves for the challenges and possibilities. This process of envisioning the future gives social movements some clarity and impetus to create their own futures, rather than being dependent on external circumstances. The business case created by the national association (CAILC) in 2003 is an excellent example of a social movement building a vision and a document to guide their future directions.

As we conclude our history and analysis of the Independent Living movement in Canada, it is helpful to examine some of the major issues that impact the movement now and into the future. We begin by reviewing some of the strengths of this complex social movement. In 1992, John Lord and his colleagues completed a descriptive study of the then six Independent Living Resource Centres in Ontario. Lord completed his review by identifying five major strengths of the Ontario centres. These are outlined in Table 56 and are still relevant to the national scene.

Table 56
Strengths of Independent Living Resource Centres*

1. **A place where the experiences of people with disabilities are validated**: The centre is a place where the person with a disability is not devalued and there is not a problem to be "fixed." In short, people are treated as people first, and as having a disability second.
2. **Leadership of staff**: The majority of staff members in centres are persons with disabilities, so the foundation of the relationship between staff and consumers is a sense of shared experience. This allows for a different type of leadership than typical service organizations that tend to be premised in the notion of an "expert" staff role.
3. **Being a learning organization**: Independent Living is dynamic and can embrace multiple solutions to any problem. Centres demonstrate the capacity for and interest in learning in a variety of ways. The growth in knowledge and research that is being undertaken at both the national and local levels is premised on the notion of a movement that is continually learning.
4. **Clear vision of what they want to become**: Independent Living Resource Centres, and the movement in general, are working toward a goal that is informed by a vision developed in the early 1980s. Although situations change and funding alters, the vision has remained clear: *Working to empower people with disabilities and to remove barriers so that responsible, self-reliant citizens with disabilities can participate, assume risks, make choices, and contribute to community life*. Moreover, the strong set of values and principles that guide centre activity, and the increasing connections and partnerships being developed with other community groups, have ensured that the Independent Living vision becomes a reality.
5. **Being part of a national movement**: Although local Independent Living Resource Centres stress their grassroots approach and community involvement, there is a keen awareness that each centre is part of a national movement as a member of the Canadian Association for Independent Living Centres. All centres are actively involved in and promote the CAILC network, the development of provincial networks, and the sharing of newsletters and annual national conferences.

* A summary from *More Than Just Another Human Service: A Review of Ontario Centres,* completed in 1992 by the Centre for Community Based Research.

We asked a number of leaders in the Independent Living movement to share their thoughts about the future. This group included some current and former executive directors of centres, as well as individuals who have shown leadership in IL, whether as researchers, activists, or movement leaders. Their responses relate to two main areas: *challenges for the movement* and *foundations for the future*.

Challenges for the Independent Living Movement

Like any social movement, as the Independent Living movement looks to the future, it faces a number of challenges. Leaders we talked with reflect their own wisdom and insights as they consider some of the ways the movement can address these concerns.

Moving the Values of Independent Living into Societal Institutions

Some leaders express concern about how the Independent Living movement can have a deeper impact beyond the world of disability. In 1990, Gerben DeJong, leading IL researcher in the United States, spoke to various leaders in Canada. DeJong was clear about the life cycle of social movements. In the early stages of a movement, DeJong said, the focus is on establishing an identity with distinct interests, commitments, and needs. He emphasized that in the early stages social movements "tend to be self-absorbed in our identity."[1] This certainly fits with the Canadian experience in the early years. Remember, for example, how early leaders debated what Independent Living should mean in a Canadian context.

DeJong also reflected on how social movements change as they mature. "As we become more secure about ourselves, we develop enhanced capacity to reach out to others and help to meet their needs through friendships, and through participation in the larger life of the community," DeJong explained. We have seen how most centres have matured in this way, with a growing number of partnerships and involvements in their communities. As we have explored, this has also been reflected in a wide range of national projects.

The tension, of course, is how the Independent Living movement and individual centres can influence the wider world, while at the same time making accommodations to that world. Gerben DeJong is once again helpful with his analysis. “A social movement cannot sustain itself by being in the streets indefinitely,” says DeJong. “Eventually, the ideals and values of the movement are assimilated by others and achieve sufficient social legitimacy in various societal institutions.” DeJong goes on to say, “At that stage, the identity and legitimacy of the movement is no longer the focal point. Instead, attention is turned to how the movement can sustain itself financially and institutionally.” As we have seen, since about 2002, the Canadian Association of Independent Living Centres has put extensive effort into these directions.

While these efforts have wide support across the movement, some leaders raise questions about how best to achieve goals of inclusion and sustainability. In reflecting on a desirable future for Independent Living, Patricia Pardo from Calgary says, “We need to become pervasive in all areas of life.” For Pardo, this means that “People with disabilities will live in a society where universal design is embedded in every area of a community, and people have full and equitable participation in our communities.” Pardo emphasizes that the national association and its network contribute to this vision by embodying the Independent Living philosophies in the services that are delivered and in their interactions with the community.

As Independent Living Resource Centres become more recognized and well-funded, they will likely experience tension between the grassroots portion of the movement and the more officially legitimized, organizational part of the movement. Some of the larger centres have already experienced some of this tension. As the first centre in Canada, the Independent Living Centre of Waterloo Region grew considerably in the 1990s. At the time, critics wondered if the organization was losing touch with its Independent Living goals.

Fred Kinsie, executive director of the Waterloo Centre, also struggled with this tension. Kinsie notes, “We’re getting lots of money to meet some of the basic needs, but in terms of the higher stuff, like self-actualization, we can’t seem to convince the government of the need.” Consumers in Waterloo were also beginning to push back and demand that the Independent Living principles be adhered to more effectively.

Sharon Garrah, a consumer who became board president, says, “Personally, as a consumer during the last two or three years, one of my biggest concerns is that we don’t stray from our original philosophy.”[2]

This struggle is in some ways natural in organizations that have become large human service providers. Standard approaches begin to creep in and hierarchical management can contribute to bureaucratic thinking. Fred Kinsie says, “We constantly try to remind ourselves of our roots.” Recently, the Waterloo Centre initiated a review process to redefine and evaluate what the Independent Living approach means for the centre and the wider community.

Patricia Pardo reminds us that, “Right now an inclusion agenda is not the driving framework on any level of community (municipally, provincially or nationally).” Pardo adds, “That is the work ahead. We are reconstructing the notion of community and society.” Pardo agrees that this is a tall order, but in the future, she says, “The national association and its network will have to evolve or not exist in their present form.”

Addressing Funding Issues

Independent Living is a unique social movement because it is not only a national enterprise, but it also provides local infrastructure supports directly to citizens with disabilities. As a new social movement, Independent Living pays attention to human rights, quality of life, and community supports that build capacity and genuine partnerships. Since its inception, this movement has struggled with funding issues. Although these funding concerns have changed over the years, leaders agree that they will continue to be a significant issue for the near future.

In 1988, when the national association signed its first formal agreement with the federal government, the first seven centres each received an annual fund of approximately $200,000. Through the 1990s, the number of new centres grew much faster than the federal government money. By 1997, each centre was receiving about $85,000, and by 2002, this had been reduced to about $53,000. This created dilemmas for centres to be able to provide the full range of core programs. Centres with multiple sources of funding have continued to thrive, but smaller ones with limited resources have struggled.

In the 1990s, the national association recognized that the federal government funding contributions to each centre would have to be reduced if new ones were to be supported. The goal at the time was to bring more provincial governments on side as funders for centres. This has happened in three provinces—Newfoundland and Labrador, Manitoba, and British Columbia. In other provinces, such as Saskatchewan, Nova Scotia, Quebec, and Ontario, some centres have been able to access provincial project or service funding, but not core funding. As Mike Murphy, executive director of the Kingston Centre says, "We need provincial buy-in from different governments to insure our long-term sustainability."

Mike Murphy

Similarly, Pierre Majeau from the Montreal Centre explains the importance of provincial involvement in Quebec. "I think that on the provincial level," says Majeau, "it is going to be necessary for us as ILRCs to take more concerted action to achieve our vision. Provincial involvement is absolutely essential to the whole issue of the future development of centres in the Province of Quebec." Majeau adds that, "The area we should concentrate on is information/referral/networking services. This field is pretty wide open in the province, and in my opinion, we have a wonderful window of opportunity before us."

Fraser Valentine, former CAILC staff person who now works for the federal government, says, "The key question involves the intersection between the guiding ideals and practical funding. Because the IL movement tends be viewed as anti-professional, it has not been able to access much professional money… Some centres have been clear about not providing direct formal services, which further keeps centres away from potential funds."

Some leaders stress the need to approach funding issues on multiple levels. This means continuing to seek provincial funding, searching for foundation grants, and developing fundraising approaches in local communities and beyond. Cathy

La France from Victoria says, "CAILC's support to centres to look at sustainability, fund development, and long-term planning has been very helpful. Giving centres some resources to actually go out into the community and develop a fund development campaign is gradually creating sustainable organizations." Despite some initial successes of the fund development process, leaders agree that dependable federal, provincial, and municipal government funding will be needed. Some leaders stress that governments have a responsibility to be continually developing citizenship and the social economy for all its citizens.

Building Sustainable Leadership

In a recent study completed on *The Role of Consumer Driven Disability Organizations in the Non-Profit Sector*, leadership was identified as a key ingredient of the Independent Living movement. The study report states that, "Good leadership has been critical throughout the history of the non-profit sector, and has been recognized as a requirement for the sustainability of the disability movement." Paradoxically, the study stresses that disability leadership is in need of renewal.[3]

Leaders we talked with also emphasized how important leadership will be for the future. Michael Horne, former CAILC staff person, envisions a future where, "there will be strong local leadership with a commitment to citizenship and partnerships." This idea of leadership builds on the work of the early leaders, who were so adept at building relationships with a wide range of people.

Yet, current leaders also bring new strategic approaches to what leadership means. Wendy Savoy, executive director of the Thunder Bay Independent Living Resource Centre, says she and her staff write up to 15 proposals every year. As we have seen, Savoy also has helped "shift" the nature of her centre's focus, from just supporting individuals to educating the community about inclusion and full participation. Future leaders must be able to embrace these kinds of strategic approaches.

Leadership for social movement leaders is no longer understood as the individual champion. It is about how we collectively build capacity and networks for change. Deborah Kennard from the Montreal Centre, for example, says, "I think that

Above: Executive Directors Forum, June 2008

Left: Thunder Bay IL Centre executive director Wendy Savoy (top right), staff and chairperson Terry Lynch (bottom centre)

it is important to establish a Quebec or francophone network in which we would all work, that would be very good. I think that to advance IL here in Quebec, it is really necessary for the public to recognize what we do and why we are different, which will help us deliver our programs better. As I see it, [a leadership network] would help a lot."

Some current leaders raise concerns about the next generation and how they tend to see their role quite differently from their predecessors. Diane Driedger from Winnipeg notes that, "Young people with disabilities are experiencing more inclusion, and are not always so ready to step into the movement. While this is a benefit for society, it is a dilemma for the IL movement." This trend reflects some success with social inclusion, as people with disabilities have expanded opportunities to participate in careers and professions. This will become an issue for the movement in the future, if this success also means that people with disabilities will turn away from social movements that work for social change in a broad variety of areas.

Other leaders reflect the concern that the movement needs to attract new leaders continually. "Maybe our organizations have to find new ways of being attractive to young people," said one executive director. "My sense is that many of the younger people are interested, do have passion…but their commitment is probably shorter term and their focus is much more specific. They're not taking the 25-year view; they're taking a two- to three-year view."[4] This trend is typical of the younger generation, who no longer view employment and volunteerism as lifelong loyalty to one organization. Some researchers have noted that young people are looking for opportunities to participate and contribute in ways that enable them to experience personal growth and creative expression.[5] These explanations could also hold true for people's experiences with the Independent Living movement.

Since the first national survey on giving, volunteering, and participation 30 years ago, the decline in volunteerism had led many non-profit groups to search for new approaches to understanding this problem.[6] In this climate of changing expectations, it is not surprising that next-generation leadership, both paid and volunteer, is of concern to current leaders in the movement. At the same time, most centres currently report quite high participation of volunteers with disabilities.

Despite these concerns, there is a sense that many next generation leaders understand the nature of leadership for these times. Tracy Knutson, CAILC board member and a leader in Saskatchewan, recently spoke to the annual general meeting of the South Saskatchewan Independent Living Centre. Knutson began by reflecting on some of the key lessons from her Independent Living experience, including the power of dreaming, the importance of respect and dignity, and self-determination as a building block for everything that centres do. Knutson's final lesson is what she called "the big one—the importance of people, relationships, and community." Knutson went on to explain that Independent Living Resource Centres provide leadership in two ways. "There's a saying that parents must give their children two things: roots and wings. Give them roots to keep them grounded through tough times. Give them wings to soar above everything, explore new worlds, and fly further then we ever did."

Figuring Out the Role of Direct Services

The original core programs of Independent Living Resource Centres did not include direct service provision. Rather, "service development capacity" was the term used to differentiate centres from typical service providers. As we have seen, this phrase has evolved to include research and community development. In both cases, the idea was for centres to develop, test, and disseminate information about Independent Living approaches to services for people with disabilities. Many examples of successful projects have been shared in earlier chapters. In some cases, successful projects have continued at ILRCs, while in other cases, projects have continued in the wider community.

Financial pressures have caused many centres to reconsider their original view of limiting their service work to research and community development. As noted earlier, centres find that government ministries fund direct services, but seldom will fund innovation, information and networking, or peer support. This dilemma means that centres may need to redefine the role of direct services in their future.

The Independent Living Centre of Waterloo Region was the first to take on direct services as part of their mandate. They did this in response to consumer demand. Consumers in Waterloo Region were clearly saying that they wanted decent, affordable, accessible housing and attendant services. As we have seen, Waterloo has delivered these services in an Independent Living fashion for 25 years. Yet, centres like Waterloo have also had their share of critics, who say that human service provision can too easily become a slippery slope that leads to hierarchical approaches and complacency.

Peggy Hutchison, a Brock University professor who has completed several studies on Independent Living, says the danger with Independent Living Resource Centres becoming direct service providers is that “it can easily distract from the important work, such as providing effective core programs…that is fundamental to Independent Living.” The reality is that direct service delivery is time consuming, and because it is usually government funded, tends to include bureaucratic procedures. Furthermore, Hutchison points out that there is an inherent “conflict of interest” when organizations provide direct services as well as advocacy supports. It is difficult for service providers to advocate on behalf of someone who is upset with a service that is being offered by the provider.

While few centres have built services to the extent that Waterloo has, many have begun to explore how they can deliver some direct services. There are both financial and pragmatic reasons for this shift. Financially, the running of direct services helps centres to pay their staff and provides important income. However, centres often get into service delivery because a pilot or demonstration program has been so successful that consumers demand that it continue.

Such was the case with Navigating the Waters, the successful seven-year project organized nationally through CAILC and funded by the federal government's Opportunity Fund. As we have described, Navigating the Waters enabled centres to provide individualized facilitation support to consumers who were interested in career development. This initiative provided a direct service that many consumers found very meaningful.[7] In addition, this approach to employment turned out to be an excellent fit with many of the core programs. When Navigating the Waters was to end in 2002, several centres found ways to keep it going with alternative funding sources.

Thunder Bay, for example, kept its employment program alive and continued to grow that initiative. Wendy Savoy explains, "Employment skill development and support is now almost a core program. It addresses a key need and is a good fit with Independent Living." Today, career development and employment support is a significant direct support service within several Independent Living Resource Centres.

Traci Walters, national director of the national association, says it is reasonable to expect centres to run some direct services "as long as these services are rooted in and guided by IL principles." Centres are moving ahead cautiously with this direct service provision. One executive director points out that it takes time to be sure that a service can be delivered with all the Independent Living principles. Services such as personal planning, direct funding, and attendant supports are by their nature individualized and a better fit with IL principles than more traditional human service programs.

John Lord, co-author of the recently published book *Pathways to Inclusion*, says that centres could become more entrepreneurial.[8] Lord explains, "If centres see themselves as social innovators, they will develop new paradigm supports for people, focus on being effective at building partnerships, and find funds from different sources." Lord notes that many regions of Canada are struggling with the limitations of traditional direct services, which are often characterized by compliance and clienthood. He says there is an important role for centres to continue to research and test out new approaches to service delivery and encourage others to become engaged in changing their direct service approaches.

As centres continue to explore whether and how they can become involved with direct services, the challenge will be for them to keep the Independent Living principles foremost in their minds. In this process of discernment, centres will benefit immensely from understanding the nature of direct services, their history, and limitations. Centre leaders will need wisdom to be sure that they limit the types of direct services to those that are individualized and consumer controlled. The emergence of what some call indirect supports, such as career development, brokerage, and independent planning and facilitation, may be the most suitable supports to consider.[9] Centres will also need to be constantly questioning, with input from their grassroot constituents, whether establishing a direct service within a centre is counterproductive to their goal of broader community integration.

Changing Demographics

We live in an aging society. These changing demographics will have an impact on Independent Living and on our wider society. While about 14 percent of our population is now over age 65, this is expected to rise to 20 percent by the year 2030. Men and women are both living longer, with the number of people over 80 expected to grow significantly in the next 20 years. People with disabilities are living much longer as well. In 1900, for example, people with Down's syndrome seldom lived into their teens or twenties. Today, many citizens with Down's syndrome live full lives into their forties, fifties, and even sixties.

Demographer David Foote from the University of Toronto argues that demographics account for about one-third of our trends and societal directions.[10] Our aging society will challenge health and human services to be responsive to older citizens. Since disability also increases with age, many more citizens will experience disability in the future. There are also important gender differences to consider. Among Canadian women over 65, only 47 percent continue to have a spouse, in contrast to 78 percent of senior men. Older women are much more likely than men to live in poverty and have limited income. Economic discrepancies and social isolation will affect the IL movement and the supports offered in the future. Some leaders note that baby boomers tend to have higher expectations about the quality of supports they receive.

How should Independent Living respond to these changing demographics? Some leaders clearly see these trends as an “opportunity” for the movement. Some provincial governments have been exploring how to respond to the expected increase in the number of senior citizens with disabilities. The Independent Living movement could teach governments about the limits of prevailing policies and practice that promote long-term care for seniors. The ILRC *Région du Bas-Saint-Laurent* in Trois-Pistoles has been involved in a research and demonstration project with senior citizens in their region. They have found that Independent Living resonates with progressive service providers in the area of aging.

Vincent Miele from the Disability Resource Centre in Richmond describes that centre’s 10-year plan. “Part of this plan,” says Miele, “is getting more people involved and active. This movement needs to be more inclusive.” Miele points out that, depending on the population, centres tend to focus on one kind of disability over another. Miele believes, “It is a good goal to be truly cross-disability.” Expanding cross-disability supports to seniors in many ways is a logical next step. By reaching out to older people with disabilities, centres will find they can apply the IL principles and engage new partners. Changing demographics, then, will be both an opportunity and a challenge to the Independent Living movement.

Foundations for the Future

When Independent Living leaders reflect on the future of the movement in Canada, some of the themes they describe are familiar and build on what has already worked well. Other themes are new, and reflect that Canadian society today is very different from the society of 1980, when Independent Living was first being introduced in Canada. Each of the following themes can be considered as foundations for the future, because they ground the movement in possibilities and vision.

Commitment to Self-Determination and Community

New paradigms in the world of disability are increasingly grounded in two key values—self-determination and community. Although historians have often considered these two values as opposites, the reality is that in a democracy these values are interdependent and highly complementary.

Leaders often describe self-determination as consumer control or consumer direction. Self-determination is about having personal control and choice, but it is also about being intentional about our choices. Tracy Knutson from Saskatchewan describes self-determination as a key lesson that we need to reinforce repeatedly. For Knutson, the South Saskatchewan Independent Living Centre's work on individualized funding best captures the essence of self-determination. A planning group was meeting with officials from the Department of Health to try to sell the concept of individualized funding. Knutson tells the story: "After many tries to explain the benefits, the message wasn't getting across. One of the officials asked the question 'Why does it matter so much who puts your socks on?' An exasperated Michael Huck replied, 'Because they're my damn socks.' The message made it through." This is self-determination in action.

Tracy Knutson with brother Larry Knutson

Knutson and other leaders emphasize that self-determination does *not* mean "doing it by yourself." Consumers who do not verbalize, for example, may need communication support to make choices. Choosing who you want to help, and choosing who you want to spend time with, are important aspects of self-determination. And they lead us to community!

Community as a value is the belief that all human beings want to belong and participate with their families, neighbourhoods, networks, and groups. Community is grounded in hospitality and civic society. Community provides the trust and relationships that are based on people's experiences of common interest. Inclusive communities are the vehicle for the expression of self-determination. As we have seen, people at centres learn to dream and take charge of their own lives. As people make choices, they begin to participate in community.

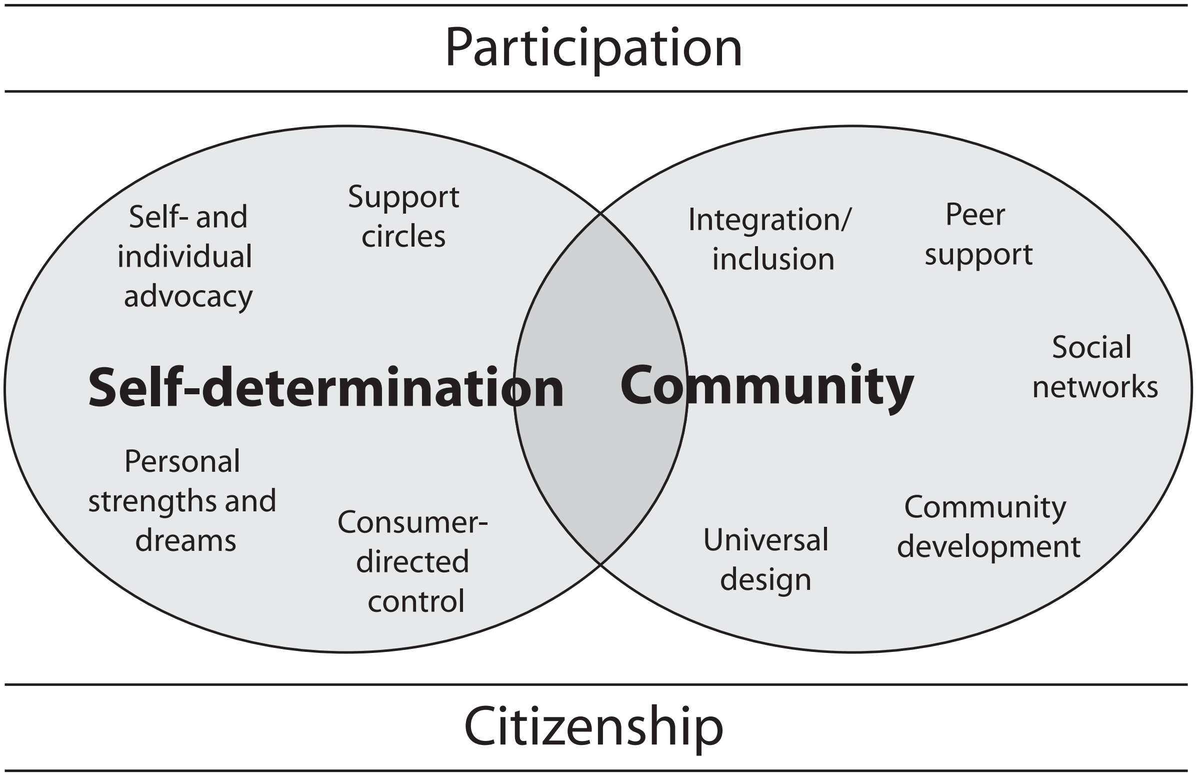
Without a strong grounding in both self-determination *and* community, Independent Living runs the risk of what Gary Woodill calls "possessive individualism."[11] Remember, Woodill was the researcher who worked closely with the Centre for Independent Living Toronto on that important document *Independent Living and Participation in Research*. There is no doubt that some Independent Living Resource Centres have overstressed self-determination with too little attention being paid to community. As Woodill points out, the reality is that market forces will not address all the needs of people with disabilities just because they are making self-determined choices. Community must be part of policy and practice with Independent Living Resource Centres, says Woodill.

As the Independent Living movement matures, it is beginning to embrace a community model of Independent Living. Sandra Carpenter, a leader from Toronto, says the vision is "consumer control and choice *within* the community." Paula Saunders from Kitchener–Waterloo finds that a community focus enables others to connect with the IL philosophy. In terms of her community, Saunders says, "There just is a real cohesiveness here that Independent Living is a good philosophy and the community wants to embrace it." Tracy Knutson says that in the future centres will need to become more concerned with interdependence. As Knutson and her colleagues have demonstrated at the South Saskatchewan Centre for Independent Living, supporting people to develop support networks builds a strong sense of community and enables people to make more self-determined choices.

As the community model of Independent Living takes hold, it is interesting to note that more and more centres are becoming engaged in community development. One leader says, "This will be a vital piece as the centres move beyond the world of disability and catch the wave of the wider community movement." In the last two years, centre leaders have reviewed the core programs and concluded that community development deserves a place with these central functions (see Appendix B). To be effective, centres know they must pay attention to the wider community, engage with it, and collaborate with others to influence the community's development.

The commitment to self-determination and community anchors the Independent Living movement in citizenship. As Mark Kingswell writes, "Citizenship is a way of making concrete the ethical commitments of care and respect, of realizing in action an obligation to aid fellow travelers."[12] While citizenship is a valued goal, some leaders point out that many centres will need additional training and support to deepen their work in enhancing self-determination and community. Table 57 outlines the elements of a community model of Independent Living. We propose here that self-determination and community will be the pillars for the future.

Table 57
Independent Living: Pillars for the Future



Tracy Knutson reminds us about the meaning of the phrase "meet people where they are at" within Independent Living. Knutson explains, "We learn this means that rather than judging and trying to fix and change people to be what we think they should be, we listen and learn who they already are, and what they need to grow. Through that process, we also learn more about ourselves and who we are. We learn that help doesn't mean doing only what we want to, it means doing what others need us to." As the African proverb says, "My humanity is bound up in your humanity" —self-determination and community intricately linked in action.

Connecting People With Information and Convivial Tools

When the Independent Living movement began in Canada, computers for office and home were in their infancy and the worldwide web was not yet even conceived. Much has changed in the last 25 years, and today advanced technology has brought many benefits to people with disabilities.

It may seem trite to say that information is power, yet people describe repeatedly the value of receiving the right information at the right time. Christine Malone, national staff person, says that improved technology can have strategic impacts. "In a way," Malone reflects, "the IL Impact Project has enabled us to set the bar higher, because we are now able to get information to people in an effective manner."

Leaders with whom we spoke see information and technology as vital developments for the future. Kier Martin represents those people in the movement for whom technology is part of their everyday lives. Sometimes known as "techies," these IL leaders across the country have been addressing what is known as the digital divide. "Why shouldn't people with disabilities have access to the best information technology?" they ask. "Why shouldn't the IL movement create the appropriate technology so that any person with a disability can receive information they require in the format they desire?"

Are the techies right in their assessment of the future? Visit almost any Independent Living Resource Centre across Canada and the answer will be a resounding "Yes." Most centres now have several computers available for consumers to access, and often the computers are all in use! In recent years, leaders have also been noticing this shift toward more accessible information technology. Sandra Carpenter from Toronto says, "We have to find a better, more creative use for technology so people don't have to travel to get involved in the IL movement."

In late 2007, CAILC launched its website Virtual ILRC. A three-year initiative supported by the federal government's Office of Learning Technologies, this project is allowing the movement to build the virtual capacity of the IL network. In addition, this virtual site will provide free online employment and pre-employment supports, resources, and tools for people with disabilities. Currently being piloted at three centres, eventually all centres will have access to the most advanced technology. The idea is to make information and knowledge available to any person with a disability. "This will be a unique resource," says Martin. "We have created technology that will have both a cross-disability and an Independent Living lens."

As technology gradually changes the way information and knowledge are shared across the movement, it is important to be sure that the technology is "convivial." This was the word adopted by Ivan Illich in the 1970s. Illich questioned the rapid pace of technological development that often seemed to lack a human face. "The key," says one executive director, "is to connect people with information and user-friendly tools." Much thought has been given to this question as the national association designs tools for a range of people with disabilities. Remember the question that Kier Martin first learned from consumers in Newfoundland: "How do you want to use the technology?" This kind of question constantly grounds the use of information technology within the principle of consumer control.

Technology continues to change rapidly and leaders see potential for a wide range of uses in the future. National projects will be able to have their own virtual sites and information will be able to be easily disseminated. The webcasts that are such an important part of the UN Day every December 3 will grow in importance. Sandra Carpenter says that even annual general meetings will be able to be accessed by consumers. Carpenter notes that, "Information technology does not change who we serve, but expands our methodologies to give people more options for accessing information."

As centres deepen their understanding of the use of appropriate technology, broader community goals should become central to the enterprise. Already, for example, some centres have linked their websites to community information centres and local libraries. This integration goal will no doubt influence future decisions about technology within the Independent Living movement.

Stay With Our Dreams

Independent Living is a strength-based movement. From the values and principles through the core programs, Independent Living honours each person for who they are. Deficits and "fixing" are not part of this culture. In this atmosphere, it is understandable that people's dreams will emerge. An important role for Independent Living Resource Centres is to listen to and support people in pursuing their dreams.

Tracy Knutson recalls her experience with the South Saskatchewan Independent Living Centre. "We had the privilege of coaxing people to dream, and listening to their hopes and fears and helping them plan to get a little closer to those wishes they make," says Knutson. She adds that, "Learning to help people to dream, including myself, has been an absolute gift to many of us. Seeing dreams becoming reality is a powerful, humbling thing… People having their own place to live, making it when many others told them it would never happen. Others going to school or getting jobs that they thought they never would."

Leaders are clear that the Independent Living movement must continue to stay with its dreams. Like individual consumers, centre leaders also have dreams, and many have been visioning their future and creating plans to build sustainable centres. Jim Harnden, executive director of the Cowichan Independent Living–Disability Resource Centre in Duncan, British Columbia, grounds his vision in citizenship. "I envision a world someday where labels won't be necessary and that we as citizens in our respective communities will be identified by our own accomplishments regardless of their importance or significance to society."[13] Harnden lives his dream by being a leader in his centre and in his wider community. He is on the Mayor's Advisory

Jim Harnden with Traci Walters outside the Cowichan IL Centre

Committee for Persons with Disabilities, is active in the Lions Club, and serves as an advisor to the Social Planning Council for his community.

Centre leaders have learned that being tenacious is an important part of staying with your dreams. Centres find that getting things accomplished in their community takes time and patience. Leaders in South Saskatchewan remember it took 10 years of work to get individualized funding in that province. Leaders in Halifax remember that it took 13 years of a pilot project on self-managed attendant services before government finally introduced a full program. And, as Lois Miller from the Halifax Independent Living Resource Centre notes, even when you do get things changed, they are not always the way you want. Another current leader expresses the hope that future leaders will have the capacity to dream and the perseverance to stay with their dreams!

As we have explored, an important part of the dream for the national movement is to become more effective at supporting diversity. Whether we are talking about expanding cross-disability approaches, ensuring that women with disabilities achieve greater equality, or reaching out to members who represent visible minorities, increasing the movement's capacity for diversity needs to be a key goal for the future.

Enhancing New Perspectives and New Partnerships

In 2008, the Canadian Association embraced a new name, a new logo, and a new slogan, "Independent Living Canada—Promoting a New Perspective on Disability." As these new elements take hold across the country, leaders express the hope that the future will be grounded in new perspectives and new partnerships.

Table 58

Independent Living
Vie autonome

Canada

Voir au-delà du handicap
Promoting a new perspective on disability

The new name—Independent Living Canada—reflects the idea that a simpler name will be remembered by consumers and the public. Interestingly, several centres have indicated that they will align their name with the new name of the national movement. In the near future, we can anticipate most centres will make this change. An example is Independent Living Vernon. This alignment of names will also help the new perspective become better known.

This new logo speaks to the contributions of the Independent Living movement in redefining disability in Canada. It speaks to people with disabilities as citizens with full rights and responsibilities. And it speaks to the contributions that citizens with disabilities are making in local communities as well as in provincial and national affairs. As importantly, the designers of the new logo wanted it to represent diversity and inclusion. Independent Living works best when centres and their communities embrace diversity and intentionally build welcoming, inclusive communities.

In imagining the future, Michael Horne says, “There will be a network of centres that embrace innovation.” Peggy Hutchison explains how research can contribute to ongoing innovation. “Research of the right nature should and could be an integral part of the everyday work of the centres,” says Hutchison. She stresses that, “Pushing the boundaries of the new paradigm happens best when research, knowledge, and practice become intertwined… CAILC will know when this happens when research is such an integral part of everyday life that it is no longer known as research.”

The paradox that Hutchison describes challenges centres to take seriously their own slogan, “Promoting a New Perspective on Disability.” This perspective is not a static outcome, but is a long-term vision that requires constant research, dialogue, community development, and innovation. Although some centres have been operating in this mode for years, others will be on a steep learning curve as they struggle with the art of becoming innovators and collaborators.

Enhancing new partnerships will be an important part of this new perspective. We have seen how the national association and many centres are already very involved in partnership development for fundraising, research, service innovation, and community development. Paul-Claude Bérubé, national past-chairperson, says, "Partnerships are important because they help to safeguard against a loss of resources, loss of energy, and loss of funding."

As we have noted, research is showing that collaboration, as a principle, is essential if communities and governments are to resolve critical issues. In future, there will be a need for expanded partnerships and collaborations for resource development and for solving social issues facing citizens with disabilities. Collaboration is rooted in our understanding that complex social issues require comprehensive thinking and multi-sector partnerships. In future, there will be many opportunities for centres to become engaged in other national and local issues such as poverty reduction, enhancing inclusion, or reducing loneliness.

Enhancing partnerships in the future will also involve the participation of Canadians with disabilities on the international scene. David Shannon, national board member, describes the energy of expanding partnerships. "In terms of impact, we are on the precipice of real potential," says Shannon. "The movement is picking up momentum and as we grow we are becoming more refined. Independent Living is in a great position to launch internationally. If we work in partnership at an international level, we will launch this thing through the stratosphere."

In September 2007, CAILC representatives attended the seventh Disabled Persons International World Assembly in South Korea. This assembly marked the first Global Summit on Independent Living. Canadians with disabilities played a major role in this event. Led by national director Traci Walters and national chairperson Paul-Claude Bérubé, Canadians did three major presentations. Traci Walters says the expansion of Independent Living Resource Centres throughout the world is inspiring. "In many corners of the world, IL centres are making it possible for people with disabilities to live in their own homes, in their communities, with access to services, the built environment, and employment." The Global Summit officially declared that they will take joint action toward the establishment of a global network of IL centres.

At the Global Summit on Independent Living, Traci Walters received a meritorious service medal. Walters accepted the award on behalf of the Canadian IL movement. With Canada playing a leadership role, there is great potential for the

IL representatives Meenu Sikand, Paul-Claude Bérubé, Traci Walters, Canada; and John Lancaster, and Glen White, USA, at Global IL Summit in Korea

development of new international partners in the future. As Traci Walters says, "There is so much to learn from the experiences of other IL leaders throughout the world."

Final Reflections

We began this book by describing some of the values and principles that were fundamental to the origins of Independent Living in Canada. After 25 years as a dynamic social movement, the Independent Living movement continues to embrace those initial principles—consumer control, peer support, community integration, and individual advocacy.

Over time, we have seen this social movement deepen its understanding of these guiding values and principles. Consumer control is much better understood today as a key element of self-determination. Community integration is now understood more broadly as social inclusion. Other principles have gradually emerged as Independent Living Resource Centres have developed relationships in their communities. Building genuine partnerships has become important to many centres. Also, community development has been endorsed nationally as a core program, although in many ways it is also a principle to guide how centres work with their communities.

In reviewing the breadth and depth of this social movement, we have discovered that the history of the Independent Living movement is primarily about relationships, leadership, and vision. From its founding in California, we learned how Ed Roberts and his fellow students developed the idea of a centre where people with disabilities would determine how their support services would be provided. In Canada, Henry Enns took hold of the American vision and invited several other Canadians to work with him in developing a Canadian approach to Independent Living. Allan Simpson understood that the IL vision required political support and he built relationships with politicians and civil servants. Although the key leaders of this first generation leadership are no longer with us, their legacy is grounded in the values and principles, relationships, and clear vision that built the Independent Living movement.

Second-generation Independent Living leaders have kept the vision alive, built the movement across Canada, and expanded partnerships locally and nationally. With the growth of centres across Canada in the 1980s, movement leaders realized they would need a strong national organization. Since 1993, Traci Walters and the national association have provided vibrant leadership for Independent Living Canada. Walters has helped all 28 centres to work collaboratively with the national organization and she has been very strategic in the way she has utilized national projects to build momentum for change. Walters, along with long-time national chairperson Paul-Claude Bérubé, realized in 2000 that the national association and its network needed to expand their capacity. The national board approved a number of significant initiatives, funded mostly by the federal government, that have increased the sustainability of centres and the movement.

Some of the second-generation leadership comes from executive directors of Independent Living Resource Centres. Remember Tracy Knutson, who brought energy and a spirit of collaboration to the South Saskatchewan Independent Living Centre, Mike Murphy, who brought dedication and strategic approaches to the Kingston Independent Living Resource Centre, and Mary Reid, whose pioneering spirit helped shape the St. John's Independent Living Resource Centre.

Other second-generation leadership comes from consumers who played a variety of important leadership roles, whether as national board members or as founders of local centres. Remember the impact of Sandra Carpenter in Toronto and nationally. Remember Carole Sénéchal as a founding member of the ILRC *Région du Bas-Saint-Laurent*, Trois-Pistoles, the first Independent Living Resource Centre in the province of Quebec. Remember how Dan MacLellan forged an alliance between two organizations to create the Halifax Independent Living Resource Centre. And remember the leadership of Kathy Bloomfield in Collingwood, who was the executive director and then became a very influential community member, both personally and politically.

Who are the next-generation leaders? These leaders are already in our midst, as volunteers, consumers, and local innovators. Many of the stories we have shared are about people who are "growing into leadership." While there is concern in the movement about the number and quality of next-generation leaders, many centres are reaching out to young people to engage them on committees and boards of directors. As we have learned, as consumers become empowered, they often have the potential to take on leadership roles. Young people today who have disabilities bring with them richer and deeper community experiences, often well-established relationships, and many creative ideas. A generation of inclusion has meant that the next generation has tremendous potential for leadership.

All three generations of leaders remind us that the root of much of the success of Independent Living is relationships. This includes authentic relationships between staff with disabilities and consumers and volunteers; partnership relationships between leaders and their wider communities; and relationships based on common interest between Independent Living Canada and its network of local centres. When these relationships are based on trust and sound Independent Living principles, they can flourish. Although we have noted that all parties have experienced bumps along the way, there is no doubt that when an Independent Living lens is combined with strong relationships, difficult situations can be overcome.

In addition to leadership and relationships, social movements require several other ingredients to be sustaining for the long run. They must have a vision that inspires people to do the right thing. But they must be willing and able to adjust their vision as conditions change. They must be self-critical so that they are always learning and growing. They must be able to create local infrastructure that grounds the national movement in local communities. Since their inception, Independent Living Resource Centres in Canada have served as a kind of mediating structure between a national movement and local consumers, and between consumers and their communities. As a recent research study showed, this makes Independent Living a unique social movement with extensive local work as part of a national enterprise.[14]

Despite the gains and the outstanding achievements, the Independent Living movement in Canada remains vulnerable, mostly because of uncertain funding. Like the experience of many individuals with disabilities, vulnerability can be an asset and a liability. As individuals move from clienthood to citizenship and begin to regain valued social roles, they learn that the attributes and diverse perspectives of people with disabilities is a strength rather than a limitation. Similarly, the vulnerability of centres need not make people depressed and immobilized. In most

Representatives from Richmond Disability Centre's Youth Leadership Program

cases, it is doing just the opposite, with centres seeking new social roles and becoming well-recognized players in their communities. As the Independent Living movement moves toward the future, movement leaders will need to remember to support each other though challenging and vulnerable times.

Unfortunately, the politics of disability in Canada always seem to be an uphill struggle. Despite extensive poverty, high unemployment, and loneliness among many citizens with disabilities, provincial governments continue to fund mostly traditional services, which typically do not address these significant issues. Independent Living as a philosophy and practice is now widely understood and supported by the federal government, which has been a major funder over the years. As provincial governments become more aware of the limits of their traditional services, there is hope that insights and research from Independent Living can play a role in provincial service system transformation. Some leaders continue to work with other national groups in advocating for a collaborative effort by federal and provincial governments to develop a pan-Canadian approach to disability supports.

The foundations that leaders have described—commitment to self-determination and community, connecting people with information and convivial tools, staying with our dreams, and enhancing new perspectives and new partnerships—provide a strong base for the future. To build a future of possibilities, there are many challenges that must be met. Whether resource development, partnership building, the role of services, changing demographics, or how to apply the values of Independent Living more broadly, these issues will play out in the future at both local and national levels. This social movement is up to the challenge of effectively addressing these issues and others that may emerge in the years ahead.

> *In the confrontation between the stream and the rock, the stream always wins, not by strength but by perseverance.*
>
> —H. Jackson Brown

Endnotes

1 Gerben DeJong, *The Future of Independent Living as a Social Movement*, Presentation to the Canadian Association of Independent Living Centres, Calgary, Alberta, September 1990.

2 For more detail on the Waterloo story, see Gary Nyp*, Reaching for More: The Evolution of the Independent Living Centre of Waterloo Region* (Kitchener: Independent Living Centre of Waterloo Region, 2002), 100–102.

3 Peggy Hutchison et al., *The Role of Consumer Driven Disability Organizations in the Non-Profit Sector* (St. Catharines, ON: Brock University, 2004).

4 Hutchison, et al., 14.

5 Richard Florida, *The Rise of the Creative Class* (New York: Basic Books, 2002).

6 Hutchison, et al.

7 John Lord, *Navigating the Waters Evaluation Summary* (Ottawa: Canadian Association of Independent Living Centres, 2001).

8 John Lord and Peggy Hutchison, *Pathways to Inclusion: Building a New Story with People and Communities* (Toronto: Captus Press, 2007).

9 For an extended discussion of independent planning and facilitation, see John Lord and Peggy Hutchison, *Pathways to Inclusion*, Chapter 8.

10 See David Foote, *Boom, Bust, and Echo: Profiting from the Demographic Shift in the 21st Century* (Toronto: Stoddart, 2001).

11 Gary Woodill, *Independent Living and Participation in Research: A Critical Analysis* (Toronto: Centre for Independent Living Toronto, 1992).

12 Mark Kingwell, *The World We Want* (Toronto: Viking, 2000), 5.

13 See Mary Dufton, “Making Things Happen—In Conversation with Jim Harnden,” *The Perspective* 12, no. 1 (Ottawa: CAILC, 2007).

14 Peggy Hutchison et al., *The Role of Consumer Driven Disability Organizations in the Non-Profit Sector* (St. Catharines, ON: Brock University, 2004).

Appendix A

Glossary of Terms

Barriers: Anything that prevents full and equal access/participation in any aspect of society that an individual may choose (barriers can be attitudinal, structural, etc.).

Canadian Association of Independent Living Centres (CAILC): A national umbrella organization that advances the principles of Independent Living by providing leadership and resources to people with disabilities through its network of Independent Living Resource Centres (ILRCs). Now called **Independent Living Canada**.

Citizenship: People experience full rights in the community and have inclusive involvement with access to services and supports they require.

Coalition of Provincial Organizations of the Handicapped (COPOH): See Council of Canadian with Disabilities (CCD).

Consumer: An individual who self-identifies as having a disability/disabilities and who may participate in the services and support of an ILRC. This term replaces "client" as the individual is the decision maker in any process.

Consumer Control: Individuals with disabilities have choice and control of their own lives. This is reflected in the fact that people with disabilities make up at least 51 percent of the membership of the board of directors of an ILRC.

Council of Canadian with Disabilities (CCD): The Council of Canadians with Disabilities advocates at the federal level to improve the lives of men and women with disabilities in Canada by eliminating inequality and discrimination. CCD's members include national, regional, and local advocacy organizations that are controlled by persons with disabilities and are committed to the principles of self-help and consumer advocacy.

Cross-disability: Refers to the range and variety, or combination of all disabilities. These include but are not limited to physical, sensory, psychological, intellectual, learning, and so on, that an individual identifies as part of their daily living.

Disability: Independent Living Canada and its member Independent Living centres are organizations run by and for people with disabilities. We support individuals with any type of disability including, but not limited to, invisible, mobility, mental health, sensory, intellectual and those who live with multiple disabilities. However, these are only labels and categories. In the Independent Living Movement, we believe that the attitudinal and environmental barriers in society create disabling conditions and are, rather, the result of living in a society designed by and for non-disabled persons. We also believe it is up to the individual to self-determine whether they have a disability or not by identifying for themselves if they experience barriers that prevent their full participation in society.

IL Lens: Using the IL philosophy as a critical model to evaluate programs, services, etc. This approach ensures that individuals with disabilities are equal stakeholders in the decision-making process.

Independent Living Philosophy: Independent Living is premised on the philosophy that all people with disabilities have skills, determination, creativity, and a passion for life, yet many are unable to participate fully in economic, political, and cultural life because barriers to full citizenship persist in Canadian society. These include outdated attitudes, inflexible laws and regulations, and fragmented and uncoordinated approaches to everything from hiring and housing to public transportation. The IL philosophy is not an abstract concept. Instead, it is about "a way of living" as a person with a disability in a society full of barriers. The IL philosophy in action is a process of navigating between barriers, gaps, skills, and supports.

Independent Living Resource Centre (ILRC): The ILRC supports individuals to put the idea and philosophy of Independent Living into action. Every Canadian ILRC is governed and staffed by a majority of people who themselves have disabilities. In this way, they can truly understand and respond to the needs of their members and the community. ILRCs are located in communities from coast to coast, and each ILRC reflects the uniqueness of a given community and region. Exercising full citizenship is at the core of the Independent Living philosophy and the work of the ILRCs.

Peer Support: Peer support is key to Independent Living. It 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 and to develop leadership skills, and gives assistance to individuals in exercising their rights and responsibilities. Peer support occurs in an environment of mutual respect and trust, and can be offered individually or in a group, and provided on an ongoing basis and/or in a crisis.

Rehabilitation Model of Disability: Focus is on the individual and their disability as socially abnormal. The goal is to assist individuals to regain a maximum level of "normalcy" in order to be seen as contributing members and to not be a burden on society.

Social Capital: Refers to the relationships, co-operation, partnerships, and trust that exist in communities. When organizations nurture social capital, they are mobilizing people and partnerships to assist them to meet their goals.

Social Innovation: The act of introducing a new idea or a new approach in a social context. Social innovation is an intentional way to create change and involves new ways of thinking and acting, sometimes referred to as a paradigm shift.

Social Model of Disability: Disability is seen as a social construction. The issue is the barriers in society that limit the full participation of citizens in the community rather than the disability itself. These barriers shape people's interpretations of what disability means within a society.

Appendix B

Indicators for National Information System

National Indicators, July 25, 2007

VILRC Site Indicators:

- Aboriginal on reserve
- Aboriginal off-reserve
- Métis
- Inuit
- Immigrants
- Disadvantaged workers
- Unemployed persons
- Persons with disabilities
- Seniors
- Women
- Community partnerships
- Workshops delivered
- Participants in workshops/event
- Projects developed
- Proposals submitted

Community Capacity Indicators

Information & Networking:

- # of units of service
- # of general information inquiries
- # of newsletters sent
- # of community events (for example, tradeshows, mall displays)
- # of website hits
- Other

Research & Community Development:

- # of demonstration projects/initiatives developed (for example, crime prevention, literacy)
- # of community partnerships (including committee memberships)
- # of media/articles/TV/radio spots
    - in French
    - in English
    - Bilingual
- # of disability-awareness training opportunities
- # of public speaking events
- Direct Funding Program
    - # of workshops/events for self managers
    - # of DF inquiries–non self managers # of general packages mailed
    - # of application packages mailed
    - # of applications downloaded
    - # of selection panel interviews
    - # of promotion calls to CCACs
    - # of contacts for or on behalf of self managers

Individual Capacity Indicators

IL Skills:

- # of individuals who secured employment or self-employment
- # of individuals who attended workshops
- # of individual advocacy consumers
- # of employment/pre-employment skills consumers
- # of skills building workshops
- # of consumers accessing employment supports
- # of individuals on funding/self-managed care services

Peer Support

- # of units of service for individuals
- # of peer support group meetings and activities

- # of peer groups being supported (for example, parenting groups, women's groups)

IL Movement Capacity Indicators

IL Leadership

- # of receipted donations
- # of organizations contributing in-kind contributions
- # of fee for service activities conducted
- # of memberships
    - consumers
    - community stakeholders
- # of volunteers
    - # of volunteer hours (general)
    - # of volunteer hours (board)
- # of letters of intent or proposals submitted
- # and type of funding sources (corporate, community, local, provincial)
- # of employees
    - with disabilities
    - without disabilities

Appendix C

Standards and Principles for Core Programs

DEFINITIONS, STANDARDS AND PRINCIPLES CORE THEME AREAS

January 2007

Introduction

The following document is a guide for Independent Living Resource Centres (ILRCs) as they provide ongoing supports and services in the four core theme areas. It is important to understand the philosophy and values on which the work is based.

Independent Living is premised on the philosophy that all people with disabilities have skills, determination, creativity, and a passion for life, yet many are unable to participate fully 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 and housing to public transportation. 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.

The Canadian Independent Living Movement and ILRCs were founded on the following five principles:

1. Consumer control;
2. Cross-disability;
3. Full participation and integration of all people with disabilities;
4. Community based; and
5. Not-for-profit.

These values are the basis of the core theme areas outlined below. This approach is referred to as the "IL lens" and is applicable to all supports and services that ILRCs provide. The broadness of the core theme areas recognizes that services, programs, and methods of delivery are unique and are responsive to the needs of local communities across Canada.

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 ILRCs 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 (for example, employment, housing, disability supports);
- Information to be provided in a variety of ways (for example, brochure racks, community bulletins, website links);
- This collection of information to be promoted and open to the public;
- Staff support to be available to respond to general inquires 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 (for example, hard copies, information exchange through meetings or by phone). Responses are to be completed in a reasonable period;
- 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 a minimum of two times per year;
- Demonstrated commitment to creating partnerships and networking in the community by:
    - Staff/volunteer involvement in appropriate community-based activities (including committees and boards);
    - Information forms as a means of updating consumers on a variety of topics;
    - Booth displays;
- ILRCs 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 and social service resources; information on government programs; computer and 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 and develop leadership skills, and gives assistance to individuals in exercising their rights and responsibilities. Peer support occurs in an environment of mutual respect and trust and can be offered individually or in a group, and can be provided on an ongoing basis and/or in a crisis.

Examples of peer support can include, but are not limited to, the following: self-help; problem solving; stress management; opportunities to join social activities (for example, diners' clubs, recreational groups); and other issues 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 (including in-person group, one-on-one, telephone network, on-line message boards) depending on consumer preference;
- Offer personal growth workshops (for example, communication skills, self-advocacy);
- Actively engage peers in planning, delivery, and evaluation of activities (including monthly group meetings, advisory committees, evaluations);
- Develop groups of special interest to consumers based on the needs identified (for example, parenting, women's groups);
- It strongly advised that an individual with a disability be in the position of coordinating peer support activities;
- Volunteers who are in mentoring relationships (for example, one-on-one,

board development) 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 in exercising 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 proactive, 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 (for example, in areas of housing, social assistance, human rights);

    - Creating opportunities for the development of tangible skills (for example, computer training, pre-employment skills) by accessing local experts and/or persons with disabilities¾or 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.

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; 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.

Index