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**Home Care, Home Support, Personal Assistance: the Co-operative Model in  
Context**

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## **About The Occasional Papers**

The British Columbia Institute for Co-operative Studies will periodically publish research papers on co-operative subjects, particularly those concerned with the co-operative movement in British Columbia. The papers will be by both scholars within the academy and interested members of the public. The Institute hopes these papers will increase understanding of, and discussion about, the co-operative movement and ideas, past, present and future.

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*Organising Fishery Co-operatives in British Columbia: The Legal and Policy Framework.* Produced by the Environmental Law Centre for BCICS.

# Preface

The British Columbia Institute for Co-operative Studies, among its various activities, is engaged in the preparation of studies into existing and new co-operatives of use to the people of British Columbia. Whenever possible, it seeks to help students and faculty interested in expanding their research interests to include consideration of the application of the co-operative model within the province.

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# Abstract

The co-operative model presents opportunities for innovation and local control over development; these possibilities are particularly relevant in the field of health care. Here, I look at the co-operative model in the context of home care and home support. The objectives of this research are three-fold:

- o to discover how co-operative models of community economic development can meet the needs of both consumers of home care/home support and the providers of that health care;
- o to consider available case studies, focusing on the impetus for development of particular co-operatives; and
- o to reflect upon the need for home support co-operatives in the Capital Health Region, Vancouver Island, British Columbia.

This report has three components. The first part is an introduction to concepts important to a discussion of health, home care, home support, and co-operative development. In the second component I provide description and analysis of two models of co-operatives working to provide home care/home support to consumers. Finally, in the third part I examine the potential for co-operative home support delivery as an alternative to the current models of home health care.

I devote attention to the conceptualisation in order to lay the groundwork for the rest of this research and discussion. It also provides the foundation for my contention that concepts, placed in context, provide the impetus behind co-operative development. My conceptualisation combines an analysis of the meaning of terms that are used to describe people's health status with a practical look at health care and how it could better serve us all as users of the system. Furthermore, it sheds light on how co-operative forms of organisation provide people with disabilities an opportunity for empowerment. In this respect, I hope this research will be useful as an educational tool for anyone interested in examining a potential application of the co-operative model.

## **Acknowledgements**

In the writing of this report numerous people shared their thoughts, time and experience with me. I would like to thank the following people for their contributions to this research project: Kari Krogh, Laura Sjolie, Kathleen Gablemann, Steve Janick of NJ PAS Co-op, Simi Litvak at the World Institute on Disability, Rick Surpin of CHCA, Dr. Adolf Ratzka of STIL, Mary Signatur and Claudia George of Senior Home Care Cooperative. I would also like to thank my friends and co-workers in the Home Support Action Group for their tireless volunteer crusade to reinstate and restructure publicly-funded home support in the Capital Health Region.

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### 1.0 Introduction

The British Columbia Institute for Co-operative Studies is concerned with understanding the nature of the co-operative model: how it functions within different contexts, how it can be used for meeting people's economic and social needs, and how it can empower individuals and communities in claiming the right to choose and control some of the forces that shape their lives.

“A co-operative is an enterprise owned and democratically controlled by the users of the goods and services provided. Users can be consumers, employees, or producers of goods and services” (Co-operatives Secretariat, 1998, p. 1). The co-operative model presents an opportunity for innovation and local control over development, something particularly relevant in the area of health care. According to the democratic view that those closest to a problem should have some say in tackling it (Chappell & Prince, 1994), the co-operative model is valuable in four areas that are particularly relevant to public service delivery and health care:

1. Co-operatives ensure control by users of the service and that the product or services will meet user needs;
2. Co-operatives have both a social and an economic mandate, which mirrors the most important goal of the public sector, that of attempting to balance social and economic development with the highest public benefits;
3. The democratic structure of co-operatives makes the service provider accountable to citizens;
4. Co-operatives provide an organizational structure, which encourages citizen involvement. (Co-operatives Secretariat, 1998, p. 1)

According to the World Health Organization (WHO), health is “the extent to which an individual or group is able, on one hand, to realize aspirations and satisfy needs; and, on the other hand, to change or cope with the

environment. Health is therefore seen as a resource for everyday life, not the objective of living...” (WHO in AOHC 1992: 1). In many cases, Canadian health care service delivery has not provided people with disabilities<sup>1</sup> or seniors<sup>2</sup> with the means or the opportunity to define the type, quality, and amount of publicly-funded health care services available. This lack of control significantly affects peoples’ abilities to maximise their health. Similarly, many home support workers earn low wages and have few opportunities for career advancement, receive few benefits, have low societal status, and have limited ability to impact their employment circumstances. For these reasons, and specifically due to the lack of integration (or un-holisticness) of Canada’s health care system, I think it is appropriate that both health care consumers<sup>3</sup> and health care workers look to co-operation as a way of empowering themselves and improving the conditions of their lives. Effective health care delivery is inherently connected to the relationships between consumers and providers.

This research into home care and home support has three components. The first is an introduction to concepts important to a discussion of health, home care, and home support. This conceptual discussion is deliberately presented as a foundation for my later discussions. I hope to alert the reader to how I use certain words; I also want to stress the importance of how we use language in our daily lives. Through my life experiences, my research, and my analysis of several home care/home support case studies, I have come to understand that an under-contemplated aspect of co-operative thought and practise is the process of communicating the vision of the co-operative developers and also the politics behind that vision. The goals that people envision for their co-operative, particularly in situations where such development is pursued by people who are marginalised<sup>4</sup>, tend to be nested in a worldview which differs from that of policy makers. The implications and ramifications of these differences are manifold, and often not conducive to successful outcomes. I hope to demonstrate this by deconstructing<sup>5</sup> the terms disability, aging, independent living, and home care, home support, and personal assistance. I argue that thinking critically about each of these concepts is a necessary precursor to understanding the rationale behind choices made in

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co-operative development, and will lead to more meaningful interactions and new understandings between people living in diverse realities.

In the second part of this paper I provide a description and an analysis of two models of co-operatives that are working to provide home care and home support to consumers: Co-operative Home Care Associates, a worker co-operative located in New York City, USA; and STIL, the Stockholm Co-operative for Independent Living, a consumer co-operative located in Stockholm, Sweden. My intention is to provide information that contributes to a resource base for people interested in other future developments.

In the third section I examine the potential for co-operative home support delivery as an alternative to the current models of home health care. I have chosen the Capital Health Region, Vancouver Island, British Columbia for the following reasons. First, I live and work in Victoria and have been following the cuts to home support in this region since January, 2000 (although the cuts first started in 1994). Second, I have been fortunate to be able to work with a dedicated community action group in Victoria. Last, I have ties to a pilot personal assistance co-operative, which seems a logical next step for BCICS research in this area.

I address the context of cuts to home support funding in this region, and look at the forms of community mobilisation which have occurred to bridge the gap between the requirements of consumers and the services provided by the provincial health care system. I contend that co-operative home care/home support could meet the needs of consumers, in that this model meets the three preconditions outlined by Drake (as cited in Krogh, 1996) in his discussion of consumer participation within the voluntary sector:

1. consumers must have the capacity to actually exercise power,
2. consumers must have authority, and
3. the role must be situated within networks such that the exercise of power is effective. (p. 29)

A corollary to this section is my inclusion of a proposal for future action,

specifically in the form of participatory and action research, using the Partnership Agreement Framework as outlined by Krogh (1996) and others. This proposal for future action would involve working in partnership with people in Victoria to start up a home support co-operative. This pilot project, the Personal Assistance Co-operative Society, began in July 2000.

I have tried to make the ideas herein interactive and to link the concept section to the case studies by highlighting questions and points to keep in mind in each section of the report. This report should not be taken as a 'how-to' manual, or a reflection of research done 'on' people, or even to 'help' marginalised people. On the contrary, I have strived to reflect and affirm the lead already taken by people in co-operative development, and, in the 'co-operative spirit', to confirm their power, agency, and choices. I hope readers will find their stories engaging, informative, and even inspiring – such is the co-operative movement as I see it.

### **2.0 Research Methodology and Objectives**

I conducted my research in the months from May to September 2000. In the course of library and internet-based research, I consulted both primary and secondary sources. An important part of the research process was my close collaboration with the Home Support Action Group (HSAG), based in Victoria, British Columbia. HSAG has been active in this region since November 1999, advocating and lobbying on behalf of people with disabilities and seniors in an effort to stop federal, provincial, and regional funding cuts to home support, as well as educating the public about the link between citizenship rights and home support for people with disabilities and seniors. In conducting the case studies, I mostly relied upon secondary sources for information. I did contact (email, telephone) the Executive Directors of both STIL and CHCA and have used the information from those exchanges to verify my other findings. I have tried to represent both co-operatives realistically and accurately. However, in accordance with my research foci

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and objectives, I have made my own interpretations:

This research has three main objectives:

1. To discover how co-operative models of community economic development work to meet the needs of both the consumers of home care/home support and the providers of health care services;
2. To consider the efficacy of available case studies, looking for opportunities to learn from the successes and obstacles faced by other co-operative development initiatives;
3. To reflect upon the need for such co-operatives in the Capital Health Region, Victoria BC, and suggest a model for home care/home support co-operative development in this area.

In each section of the report I hope to provide valuable information, as well as an extensive reference list and links to related sites. The case studies section of the report includes a list of all of the resources located during the process of this research, with the intention that these contacts will be useful to people looking to start up a home care/home support co-operative. This report is also available on the BCICS website: <http://web.uvic.ca/bcics/>

### **3.0 Concepts**

- 3.1 Introduction to concepts – why are they important to co-operative development
- 3.2 Disability
- 3.3 Aging
- 3.4 Independent Living
- 3.5 Home care/home support/personal assistance

#### **3.1 Introduction to concepts – why are they important to co-operative development?**

We have all heard the expression “knowledge is power.” One of the basic elements of power is that those who have positions of power are able to manufacture ideas. Another is being able to place ideas that have been created into the public agenda (Kirby & McKenna, 1989, p. 23).

My intent in looking at the role of concepts in co-operative development is two-fold: first to lay the groundwork for the rest of this research, and second, to put forward the argument that concepts often provide the context for the impetus behind co-operative development. It is my experience, that many people live their lives politically – we act according to our worldviews and value systems. Kirby and McKenna (1989) state that “theories reflect the political world views of the people writing them: how they see the world, where they think it ought to go, as well as how they see that happening and the direction it should move in” (p. 36). I hold that co-operative development is tied to the political world-views of people working to start co-operatives, many of whom have not had the power to define public agenda in the past. In this respect, co-operative development is not theory but action: it is about people mobilising to change the circumstances of their lives.

Language is powerful – the language we use dictates how we are

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able to define and communicate our thoughts. Language is grounded in the beliefs of the speaker, and can be interpreted in unpredictable ways through the filter of the listener's consciousness. Because language is necessary in communication, communication is crucial in partnerships, and partnerships

**"You throw like a *girl!*"**

I have been teased with this little dig more times than I can count. What does 'throwing like a girl' mean? I use an immature throwing pattern. I can't throw far, I have terrible aim, I was the bat girl on my elementary school baseball team. Is this lack of skill because I am a girl? Do all girls inherently throw as poorly as I do? Is there some physiological defect present in girls that makes us unable to throw 'like a guy' (ie. well)? Obviously not, yet still we use the term 'like a girl' as a synonym for 'pathetically bad.' This association is one example of attitudes coming across through the language we use.

between stakeholders are critical to successful co-operative development, we must consider the way we use language to articulate what we mean, why we have chosen a particular line of action, and how we intend to get things done. People involved in co-operative development must be aware of the power invested and represented in language.

When consumers of health care and workers engaged in health care service provision move toward taking control of their employment and their health we must be aware of the ensuing shift in social relationships that will occur.

Because language reveals and influences attitudes, it holds the potential, through thoughtful use, to give people more control in their lives. Since co-operatives are offered as a way for people to realise personal and collective empowerment, we must take the time to consider what people involved in co-operative development mean when they choose specific language to describe their efforts. To use language uncritically in co-operative development amounts to ignoring the small but important steps toward empowerment contained in the process of communicating and learning to define ourselves and make important choices in our lives.

The concepts I have identified that underlie discussions of home care/home support co-operatives are disability, aging, independent living, and home care/home support/personal assistance.

### 3.2 Disability

The rhetoric of social policy reform is a political language with its own vocabulary. As a tool for analysis, the concept of rhetoric calls attention to the arguments and ideas expressed as well as to the style of language used and the intended effects. Political rhetoric ... project[s] certain images, either intentionally or unintentionally, ... [and] is often policy making as symbolic action” (Chappel & Prince, 1994, p. 1).

The nature of co-operative development demands that people with both mutual and diverse interests work together in order to meet their goals. Audet and Rostami (as cited in Krogh & Lindsay, 1999) define a partnership as:

A relationship involving two or more organizations that have agreed to work cooperatively with the common goal of addressing a human/community set of issues. A partnership requires the sharing of power, work, support, and information with others. Through mutual agreement and shared values, a partnership confers benefits on each partner as well as the community, while fostering an achievement of ends that are acceptable to all participants (p. 224).

In accordance with co-operative principles (International Co-operative Alliance, 1995), any effort of co-operative development must strive to meet the criteria outlined in this partnership framework. Open dialogue to determine what each person means when they describe their intentions for

To clarify the importance of language, consider the following example. Many words used to describe the health status of people with disabilities and seniors suggest a state of helplessness for those described. Terms such as “crippled,” “house-bound,” “suffering from,” “afflicted with,” “wheelchair-bound,” “elderly,” “infirm,” when used thoughtlessly, carry the connotations of an institutional relationship to government social assistance programs. The role of the “disabled” and “elderly” is taken as passive and objectified, which necessarily grants an active, helping role to the “young” and “abled.” A further implication of government as ‘charitable provider’ is that seniors and people with disabilities must not only show their gratitude, but also they must appear to their ‘benefactors’ as passive recipients. This position is one of relative powerlessness as it is difficult to demand one’s rights when one is seen to be (or described as) dependent on the charity of others. Thus, even when these implications are not the intent of the user of objectifying terms, they are nonetheless still present as bias in the language and represent a misunderstanding of what it means to age and become disabled.

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the co-operative can help bridge the gap between diverse people's values, as well as create a clear, mutual understanding of what success means to each individual involved. Failing to articulate the belief systems of all partners in development amounts to basing development efforts on presumed meanings of concepts that are critical to the start-up process and eventual success of the co-operative.

Unconscious social beliefs influence peoples' behaviour. Beliefs manifest themselves in covert as well as latent forms, sometimes prompting us to form judgements about people based on stereotypes. Kari Krogh's (1998) illustration of the importance of power, beliefs and values in the development of community partnerships that include marginalised groups is very relevant to this discussion. Krogh, in her development of the Partnership Agreement

Social dominance is maintained along racial lines by the same covert mechanisms as are power differentials within partnerships. In Canada, racism tends to be perceived only in extreme forms, blatant and condemnable. Yet our society, stemming from liberal ideals, is based to the very core on racial systems of classification. Consider the explanation of the 'liberal paradox' offered by Frankenberg (1997); "Liberalism [which is committed to equality] seeks to transcend particular historical, social, and cultural differences: It is concerned with broad identities which it insists unite persons on moral grounds, rather than with those identities which divide politically, culturally, geographically, or temporally. ... Racist expressions are generally reduced to personal prejudices of individuals, to irrational appeals to irrelevant categories, to distinctions that delimit universal liberal ideals. ... Racism is deemed a singular phenomenon, ... a premodern prejudice, one that enlightened modern meliorism takes itself to be overcoming through the force of reason. ... The concern then shifts to managing 'race relations' (p. 5-7)." In Canada, we manage our race relations by upholding tolerance of difference in a Multicultural society, missing entirely the paradox that tolerance presupposes that its object is not only different but morally repugnant, thereby maintaining the original system of racial classification. In the same way that racism in general is perceived as individual acts of poor judgment and/or deviant behaviour, prejudice against disability is really only considered as such when people are overtly rejected from a job or housing or transportation. The mechanisms by which non-white people are racialised (objectified) share some similarities with the way disabled people are distanced from 'the norm.' It goes unrecognised that the assumptions we make about what it means to be disabled, (that people with some kinds of disabilities are asexual, incapable of parenting, incapable of making decisions and controlling their lives), are a form of systemic prejudice just like racism, and are entrenched in our health care system.

Framework, looks at factors, which may lead to difficulties in partnerships. Bourdieu and Passeron (1977) explore processes involved in reinforcing and replicating dominant relations of power in society. The authors define oppression as the imposition of meanings in a manner that conceals power relations and social dominance by particular groups. Krogh (1998) expanded upon this further in her analysis of theories of social construction to state that social dominance is strongest when it achieves its effect while remaining unrecognisable.

Social interaction within partnerships is influenced by power differentials, particularly those unexamined, as well as people's reactions to difference. Many people with disabilities feel that the reality of disability is thoroughly misunderstood by the 'temporarily able-bodied' general public.<sup>6</sup> For nondisabled people, persons with disabilities seem to represent the rejection and fear associated with imperfection, failure to control the body, as well as a person's vulnerability to weakness, pain, and death (Krogh, 1998). This mutual misunderstanding is counterproductive to forming successful co-operatives between people with diverse lives. If we wish to value different perspectives in co-operative development, we should be encouraging a process of illuminating the commonly accepted assumptions that divert our attention from the truths of people's realities. It is important for people involved in co-operative development to consider beliefs about ourselves and others, and particularly the implications of those beliefs on multi-stakeholder partnerships. Belief systems are important because they can be reinforced within both the institutional structures of society and partnership practices (Krogh, 1998, p. 127).

There are at least three distinct models<sup>7</sup> of disability, each grounded in different belief systems. What follows is an examination of different ways of looking at disability, and what these differences mean to people involved in the development of home care and home support co-operatives.

The core of any partnership is the belief systems of its members (Krogh,

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1998). Wolfensberger (1975), when writing on the origin and nature of our institutional models, looked at the correlation between the residential or institutional model and perceptions of the retarded [sic] person's role. Wolfensberger found that:

It is a well-established fact that a person's behaviour tends to be profoundly affected by the role expectations that are placed upon him. Generally, people will play the roles that they have been assigned. This permits those who define social roles to make self-fulfilling prophecies by predicting that someone cast into a certain role will emit behaviour consistent with that role. Unfortunately, role-appropriate behaviour will then often be interpreted to be a person's "natural" rather than elicited mode of acting. (p. 2)

This concept of the self-fulfilling prophecy is equally important in co-operative development. Beliefs can influence the decision to involve certain partners, the roles that people are designated within a community partnership, and/or the value placed on certain forms of expertise and contribution. Models, which may influence people involved in the thinking associated with co-operative development, are the medical model, the charity model, and the social model of disability.

### *The medical model of disability*

The traditional medical model of disability is rooted in the work of American sociologist Talcott Parsons and his discussion of sickness and sickness-related behaviour (Barnes, 1998). Parsons worked and wrote in the late 1940s. He argued that the 'normal' state of being in the Western world is 'good health,' consequently sickness and impairments are deviations from normality. The legacy of his work lives in the work of sociologists, many of whom have focussed on the 'experience of illness' and consequences, which flow from it (Barnes, 1998).

The medical model of disability, when applied unconsciously by people

in decision-making roles, is disempowering for people with disabilities. Health care professionals who adhere to the medical model of disability tend to define the type of treatment appropriate for the disabled individual. The medical model defines healthy people as ‘normal’ and disabled people as ‘abnormal.’ It is ‘normal’ people who decide the treatments that will be available and who, consequently, have the power to define how people with disabilities will live.

**NOTE:**

· How do language, power, and partnerships interconnect in co-operative development?

The World Health Organization’s International Classification of Impairments, Disabilities and Handicaps (ICIDH) is nested in the medical model of disability.<sup>8</sup> Impairment is defined as any loss or abnormality of psychological, physiological, or anatomical structure or function; disability as any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being; and a handicap is defined as a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, social and cultural factors) for that individual (Barnes, 1998). These categories are all premised on two assumptions: first, that disability is constituted by the functional limitations of a person; and second, that these limitations are different (and implied to be worse) than the norm.

Those who employ a medical model tend to focus on the impairments of a consumer, rather than the contributions that people with disabilities could make to the joint task at hand. Often people with disabilities have been seen as ‘medical cases’ needing to be ‘fixed,’ and/or objects of care, pity, and protection. These widespread attitudes have been obstacles for disabled people on their way to self-determination, self-representation, and full citizenship. For this reason, many people with disabilities find the medical model to be incompatible with the development of successful co-operatives.

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### *The charity model of disability*

The charity model of disability assumes a lack of capacity of people with disabilities. People involved in co-operative development employing this model may assume that a participant in a partnership who has a disability should be a passive recipient of assistance, rather than an active and critical member of a work team (Krogh, 1998). Krogh quotes a service provider, involved in one of the workshops, who spoke of the charitable approach toward people with disabilities:

Particularly with people with disabilities, the approach that we've taken as a society is that we have to take care of them. And we know best. And we created all sorts of infrastructures that went along with the idea of how they should be taken care of ... they've certainly been a people that have been disempowered. (p. 127)

Thus the charity model of disability is a form of socialisation, which instructs the non-disabled to take care of the less fortunate and the disabled to be grateful for that charity. In this scenario, there is no room for control or agency in the 'helped.' This model is therefore inappropriate for co-operative development initiatives involving people with disabilities.

### *The social model of disability*

The social model of disability focuses on the interactiveness of disability. Disabilities, according to this conception of them, originate in the beliefs and practices that pervade society. Brisenden (1998) states:

A disability results from the things one is not able to do because of the organization of the world around you; its causes are predominantly rooted in external social factors. ... Society disables us by taking away our right to take decisions on our own behalf.  
(pp. 25-6)

According to this model, disability is an essentialist, arbitrary definition,

characteristic of a non-disabled reaction to disability. Social model theorists have questioned the dominance of the medical and rehabilitation paradigms, which seek to transform, normalise, and/or 'cure' the disabled body (Brisenden, 1998).

The social model of disability looks beyond so-called functional impairments of disabled bodies into the structure of society, geared toward able bodies, and suggests that, rather than peoples' health status it is society's preconceptions that disable people. According to the World Health Organization's (WHO) 1984 definition, health is the extent to which an individual or group is able, on one hand, to realise aspirations and satisfy needs; and on the other hand, to change or cope with the environment. Health is therefore seen as a resource for everyday life, not the objective of living; it is a positive concept emphasising social and personal resources, as well as physical activity. To accept this definition of health, we must stretch our conceptions of illness and wellness beyond commonly accepted limits. Disability cannot be simply limited to physical ability or lack thereof, as it is also related to social and environmental conditions, which affect an individual's ability to interact with society at large.

Conflict is likely to occur between people who adhere to and behave according to different models of disability.

The social model of disability calls into question our tendency to categorise things according to binary oppositions, to define disabled according to what normal is not. Thinking in terms of oppositions is quite common:

White	Black
Male	Female
Good	Evil
Straight	Gay
Young	Old
West	East

When we think in such terms we allow ourselves to essentialise things and squish life into boxes; one, or the other. In doing so, we ignore the gray area; the continuum of experience in between the two poles.

### 3.3 Aging

NOTE:

- How are belief systems relevant in co-operative development?
- How do we define what is normal? Whose notions of normality have been used to construct institutional models of health care delivery?

“If in the past the social character of old age was structured at the micro level by family, kin and community, then today it is structured at the macro level by [state] institutions” (Myles, as cited in Chappell & Prince, 1994, p. 5).

Canada’s social safety net, developed in earnest after the Second World War, reflects societal expectations that the state, rather than voluntary associations, churches, neighbours, or families, will be the provider of services and supports for people during unemployment, illness, and/or old age. Structural explanations of welfare state development and social policy

tend to regard old age as a “basic social risk for which some form or forms of assistance and insurance need be provided by the state” (Chappell & Prince, 1994, p. 4). Welfare state policies, in part, transformed old age into a social category and eligibility principle related to retirement status and to age-based public entitlement programs. According to this perspective, elderly people are viewed as among the most vulnerable members of the community and most deserving of help and protection from government policies and programs (Chappell & Prince, 1994). Yet, most older people consider themselves neither weak nor vulnerable, especially those who have been able to maintain control and choice in their lives. Home support is a form of assistance that, when affordable and present at adequate levels, can support independent living for seniors with different health care needs than younger adults.

By the year 2030, the age group of 65 and older will constitute twenty five per cent of the Canadian population (Zimmer & Chappell, 1993). Among other factors, this growth is due to an increasing life expectancy, decreased birthrate, and the aging of the baby boom generation. Wilner and Wyatt, in their 1998 study *Paraprofessionals on the Front Lines: Improving Their Jobs – Improving the Quality of Long-term Care*, reflect upon the fact that nearly thirty per cent of a total of 42.7 million people in the United States with limitations that restrict their basic activities need assistance with personal

maintenance, hygiene, and household maintenance tasks. They attribute the dramatic increase in the demand for long-term care services to the aging of the population: “people are living more years with chronic disabilities; new technologies and medical breakthroughs have enabled younger people with disabilities to survive traumas and illnesses; and new medications are extending the life spans of persons with HIV and AIDS...” (Wilner & Wyatt, 1998, p. 9).

Seniors are emerging as a vital consumer group. As seniors become more active both economically and politically, policy makers and business communities must adopt strategies, which reflect the concerns of older adults. The three primary foci for seniors markets include products for a substantial number of healthy and active seniors who seek to maintain a healthy and active lifestyle; products to enable seniors, who have undergone health and mobility changes, to maintain their independence; and products for seniors who have substantial health and mobility problems and who are dependent on formal and informal support systems/aids (Zimmer & Chappell, 1993, p. iii). In Canada, public health conditions have improved the chances of living a long life, but parallel improvements in the health care system that are geared toward quality of life, have not necessarily occurred.

Age is both a stage and a process, but, like disability, is in no way a fixed category. Many words we use when describing ‘seniors’ carry connotations of stereotypes of the ‘elderly,’ which are common in youth and beauty-centered North American society. Zimmer and Chappell (1993) looked at the implications of conventional portrayal of seniors in media in the

An example of a home care co-operative, arising to meet the need for independent living opportunities for seniors, is the Senior Home Care Cooperative in Chicago, Illinois. The Senior Home Care Cooperative, as yet still in process, would provide an alternative for seniors which does not currently exist. The option they hope to provide is for seniors to receive home care in a setting in which they are able to maintain their identity and some control over their lives, surrounded by family and friends - in an environment where aging is valued and affirmed. The co-operative venture, with its joint ownership and shared care giving, will empower people who, by working together, will be able to provide a good quality of life for elderly family members (C. George, personal communication, June 15, 2000).

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study *Neglected Needs and Emerging Opportunities in Seniors' Markets: An Argument for Future Research*, and examined how seniors, to date, have been a relatively neglected consumer group. They state “this neglect is due, in part, to the stereotypical caricature of seniors, portrayed through various media outlets, as frail, powerless, inactive, uninterested and struggling to survive on meager incomes” (pp. ii-iii). We need to address these socially prevailing images that make old people out to be uniformly gloomy and change them into a more realistic picture of the activities of self-reliant and independent older people (M. Ohya, personal communication, October, 25, 1999). Although a large proportion of people over 65 years of age are healthy and not in need of care, there exist few organisations through which they can participate and make use of their skills, experience, and wisdom.

**NOTE:**

· What is being ‘politically correct?’  
In light of the preceding discussion, how might using words like ‘the elderly’ or ‘old and infirm’ impact people?

An interest among policy makers in social support and community care is tied to an awareness of the aging of the Canadian population, including a concern with their use of health services and an awareness that seniors themselves do not want their problems medicalised or to be treated as no-longer functioning members of society (McDaniel, as cited in Chappell & Prince, 1994). For these reasons, in this research project I will avoid ways of describing older people that sweep them into categories implying pity and powerlessness.

### 3.4 Independent Living

People who are dependent on others for the most basic needs of life face prejudices. Given their physical dependency the conclusion is close at hand to consider them as dependent on others also emotionally and intellectually. Somebody who cannot pull up his or her pants like a small child, may be treated as a small child in other areas as well. It is no surprise then that the Independent Living philosophy is most easily grasped by people who need personal assistance. (Ratzka, 1998, p. 2)

The Independent Living movement describes a place in society from which people with disabilities can participate as equal members. This equality is rooted in concepts of control and choice: people with disabilities demand the right to take risks and seek rewards, to have the same opportunities as able-bodied people (Brisenden, 1986). Adolf Ratzka (1998), the Director of the Stockholm Cooperative for Independent Living (STIL), describes eloquently the philosophy of the Independent Living Movement upon which STIL is based:

Independent Living is a philosophy and a movement of people with disabilities who work for equal rights and equal opportunities, self-respect and self-determination. Independent Living does not mean that persons with disabilities do not need anybody, that they want to do everything by themselves or live in isolation. Independent Living means that disabled people want the same control and the same choices in every-day life that their non-disabled brothers and sisters, neighbours and friends take for granted. That includes growing up in their families, going to the neighbourhood school, using the same bus, employment that is in line with their education and abilities, equal access to the same services and establishments of social life, culture

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and leisure. Most importantly, just like everyone else, persons with disabilities need to be in charge of their own lives, need to think and speak for themselves. (p. 2)

**NOTE:**

- How does the Independent Living movement relate to other movements such as the Women's Liberation Movement?
- How does the philosophy of independent living relate to co-operative development?

A key requirement for seniors and people with disabilities to be able to live in communities as full citizens is accessibility in the built environment including accessible housing and personal assistance. Without these features, people with extensive disabilities, either physical, emotional, or developmental, can choose only between being a burden on their families or living in an institution. Without affordable

options in home-based health care anyone released from acute care would have to rely exclusively upon family, friends, and/or the volunteer sector to meet their health care needs. These extremely limited and limiting options are incompatible with the concept of independent living; people are forced to rely on the charitable instincts of others, rather than being empowered to define/demand the quality and type of health care services they require to function independently. The philosophy of independent living is rooted in the concepts of control and choice: people using home support need to have control over the delivery and quality of their health care. It is important to understand the Independent Living philosophy in order to grasp why people with disabilities involved in co-operative development might associate different meanings to home care, home support, and personal assistance.

### **3.5 Home Care, Home Support and Personal Assistant Services**

There is an overwhelming preference among people with disabilities and seniors to remain living in their homes as long as possible (Hollander, 1999; Kassner & Bectel, 1998). While most community-based long-term care is provided informally (unpaid) by family members and friends, some people use paid caregivers, either as a supplement or as an alternative to informal caregiving. In Canada, paid caregivers can be accessed through a number of home health agencies, hospices, homemaker and home care aide agencies, and staffing and private-duty agencies, some of which operate on a for-profit fee-for-service basis while others are partially subsidised by the government. Remembering that co-operatives can be an important site of local innovation, it is appropriate that people with disabilities and seniors use home care/home support/personal assistance as a site for co-operative development as part of the empowerment process.

The phrase 'home care' is often associated with a wide range of health and social services, delivered at home to recovering, disabled, chronically or terminally ill people in need of medical, nursing, social, or therapeutic treatment and/or assistance with the essential activities of daily living. Yet home care is also an extremely selective term, used sometimes to limit potential users of publicly funded services. Due to this ambiguity, different terms have evolved out of the various models of disability and aging.

What follows is an analysis of the different meanings and uses of the terms home care, home support, and personal assistance.

#### ***Home Care***

Attitudes that do not support a sense of self-direction and self-worth among consumers are demonstrated in some of the language around health care. In some regions of Sweden, home care workers were commonly referred

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NOTE:

· Is there a practical difference between home care and home support services, or is the distinction simply one of terminology?

to as “Home Samaritans.” According to a biblical account, the Good Samaritan happened upon a stricken victim of a robbery and saved him from certain death. The term, therefore, seems to imply that the consumers’ life and well-being is completely dependent on the charitable instinct of some chance passers-by. Obviously terms like “home Samaritan,” when used to describe health care workers, suggests a dependence and passivity of consumers.

Home nursing care technically refers to care in the home involving medical procedures like intravenous therapy, ventilators, and feeding tubes. However, according to Cooperative Home Care Associates, a Home Care company is one which provides health-related and personal hygiene tasks, light housekeeping, and shopping for the homebound under contracts to hospitals or health service agencies (Adams, Gordon, & Shirey, 1993, p. 14). Therefore, the reluctance of some people with disabilities to use the term home care is understandable, as it is easily confused with home *nursing* care. The developers of STIL, the Stockholm Cooperative for Independent Living, hold that, terms like “attendant” and “care” should be avoided, since they carry institutional connotations and project the image of passivity and dependence. Use of medicalised terms, like home care, are perceived by some people as signs of attitudes that do not support a sense of self-direction and self-worth among consumers.

### *Home Support*

The term ‘home care’ is often used interchangeably with ‘home support,’ but the two actually hold a slightly different meaning. Home support is a service, which enables people with disabilities and seniors to live in their own homes in the community of their choice. This service fosters independence, empowerment, and the ability to exercise basic citizenship rights, which are taken for granted among the able-bodied general public.

Home support workers provide basic, necessary services such as:

- bathing, bowel care and other hygienic needs;
- assistance with rising and dressing;
- assistance with the activities of daily living;
- housekeeping, cooking, and laundry; and
- monitoring health and providing emotional and psychological support

Users are a diverse group including older people, younger adults with disabilities, family caregivers using respite services, people with chronic illnesses, and people recovering from surgery.

These services are of vital importance to people who are unable to physically or cognitively perform certain activities of daily living. Adequate levels of home support enable people to live independently in the community. The alternatives, forced upon people in situations where their hours of publicly funded home support have been cut or certain services have been eliminated from their entitlements, are institutionalisation, out-of-pocket subsidisation of people's personal health care requirements, or living in an unhealthy and/or risky situation.

### ***Personal Assistance***

The philosophy behind personal assistance is clearly articulated in the literature put out by the Stockholm Cooperative for Independent Living (STIL). Adolf Ratzka holds that most existing services cannot be called "personal" assistance, since they are not custom-made to the individual's needs and do not allow control and acceptable choices. This is true for both stationary institutions and their ambulatory counterparts - the community-based services of local governments or voluntary organisations. Inherent in these services is their hierarchical structure with the user at the bottom. Also, users are forced to share the common staff which, in itself, reduces choices and freedom of movement (Ratzka, 1998).

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In thinking about co-operative development, we must affirm the belief

held by many people in the Independent Living movement that “assistance at home as well as outside the home is the very key to the ability of persons with extensive disabilities to participate in their community and any language that suggests the opposite has to be avoided” (Ratzka, 1986, p. 6). The difference between home care, home support, and personal assistance is that personal assistance means:

1. the services are custom-designed to the individual user’s needs, capabilities, life circumstances and

aspirations;

2. the individual user exercises the maximum control over how the service is organised, who is to work, with which tasks, at which times, where and how;
3. the individual recruits, trains, schedules, supervises, and, if necessary, fires his or her own assistants. It is recognised that users with intellectual and mental disabilities will need support from third persons with these functions. (Ratzka, 1986, p. 3)

Generally speaking, personal assistants help with those activities which the user would have done by himself or herself, had it not been for a physical, sensory, mental, or intellectual disability. This term is preferred above others by the members of STIL because it conveys a more positive and less restrictive image than ‘home care.’ ‘Home care’ and ‘home support’ imply that assistance is needed only in the consumer’s home, which contributes to the impression of people with disabilities and seniors spending their days inactively at home, as opposed to in the community pursuing work, travel, and social and cultural

### NOTE:

- Keeping the subtle distinction between home care, home support, and personal assistance in mind, does it make sense that these concepts be explored by all of those who will play a role in co-operative development of this kind as a part of the process of development? How would this philosophical discussion contribute to the development effort?
- Who has the power in these discussions between people in different social positions to define the goals of the co-operative? Who has control over the development of the co-operative? How is locating this power important to the co-operative movement?

activities like full citizens (Ratzka, 1986).

Consumer control is important in the delivery of personal assistance services (Ratzka, 1986). At STIL, independent living means:

We all, whether disabled or not, know that doing everything by oneself is not the most efficient way. Instead, we often delegate tasks to somebody else. In that sense, anybody who supervises other persons at work is in the same situation as personal assistance users. What counts is not whether we do something by ourselves but whether we are in charge. (Ratzka, 1998)

It is this notion of consumers as experts that is the essence of the term ‘personal assistance.’

In this report, ‘home support’ is the term I use most frequently. It is the term I am most familiar with and it is the term used by the people in Victoria with whom I work. To me, home support means the provision of whatever support is necessary for people to be able to live independently. Home support is appropriate health care for people (both younger adults and seniors) with disabilities.

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### **4.0 Case Studies**

The two case studies I have chosen to include in this paper, the Cooperative Home Care Associates and the Stockholm Cooperative for Independent Living, reflect my desire to consider the philosophy behind both a worker-owned and a consumer-owned home care/home support co-operative.

#### **4.1 Cooperative Home Care Associates, Bronx, NY**

We see ourselves as not just creating jobs for people, but also creating an alternative community that people can feel really connected to, particularly people who don't feel connected other than to an immediate family member. ... It's like, this is a place that wants to organize you in, that wants you to be there as something more than a person to bring money in. I think I would define it as a community of support, a community that challenges you to grow, a community that sort of takes you where you come in and says that there is a common purpose here, meaning, among other things, to provide quality care for folks. (Brecher, 1998, p. 20)

The worker co-operative I selected is the Cooperative Home Care Associates (CHCA), based in the Bronx, New York City. CHCA is an innovative business. Its focus is on changing the quality of the home care industry and, in the process, 'growing people' – contributing to the development of people otherwise excluded from positions of responsibility and status in a company. The way CHCA has organised its workplace is of particular interest here, as the co-operative has been the recipient of several awards for innovation in business as a democratic firm. The workers of CHCA identified as paramount the value of creating an empowering workplace culture. This case study will highlight some of the extraordinary features of CHCA. For a more in depth look at the company please use the references and/or contact

information in the reference list.

### a) CHCA – Who, What, Where

CHCA was incorporated in October 1984 under the Business Corporation Law of the State of New York. CHCA was started under the sponsorship of the Community Service Society, New York's largest private social services agency. CHCA operates as a worker-owned home health care agency employing approximately 550 African-American and Latina women as home care aides in the Bronx and Harlem. Approximately 80% of CHCA's workforce was dependent on public assistance before being trained and employed by CHCA, and the majority are single mothers with young children.

#### RECALL:

· How do the belief systems of the founders and members of CHCA relate to the development of the co-operative?

Cooperative Home Care Associates evolved to address three questions:

1. Could a cooperative create 'good jobs' paying adequate wages and benefits, offer decent working conditions, provide opportunities for advancement through worker ownership;
  2. Could a profitable, labour-intensive business be established that was, at the same time, controlled by its work force;
  3. Could job ownership be an alternative to conventional charity.
- (Adams et al., 1993, p. 14)

The management of CHCA and its operational policies are determined by the employees, through the board of directors. The board of directors includes six worker-owners. Ownership of the voting stock is limited to the employees of CHCA. The worker-ownership component of CHCA was established over time, as is often the case in the development of businesses as worker co-operatives. Since there was no membership base at the outset, the sponsoring non-profit held ownership of the company "in trust" for the future workforce through controlling seats on the board. When specified milestones of financial performance and training were reached, the transition to a worker-owned company was initiated. This two-stage process was put

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in place to circumvent some of the problems that could be generated when worker-owners with little business experience take on the responsibilities of running a new and unproven company (DiMarcello, 1996). As of August 2000, 368 of 614 employees at CHCA are worker-owners. The co-operative intends to re-attain their goal of 70% worker-owners by the end of the year (R. Surpin, personal communication, July 24, & September 13, 2000).

According to CHCA, a home care company is a company which provides health-related and personal hygiene services, light housekeeping, and shopping for the homebound under contracts to hospitals or health service agencies (Adams et al., 1993). Their founding underlying premise is that good jobs are a prerequisite for high quality care.

### **b) Target Industry**

Developers of CHCA sought a business that would:

- employ over one hundred people;
- enter a growing market;
- employ people who otherwise had few job opportunities (i.e., not require prior training or experience);
- provide the potential for “decent jobs” (i.e., salaried positions of \$15,000/year, benefits, and a career ladder);
- offer a socially useful product or service. (Dawson & Kreiner, 1993, p. 6)

The team was attracted to the health care industry because it provided a very essential service and was a growing field. In particular, home care assistance was in demand and could be provided by unskilled labour. Many private firms in New York employed several hundred workers, however the jobs, as structured in 1985, were far from decent: they featured low wages, poor benefits, no job ladder, and isolated working conditions (Dawson & Kreiner, 1993). The co-operative developers thereby arrived at their key question: could a profitable enterprise be created within the constraints of the

home health care industry that would still significantly improved the quality of the home health paraprofessional's job?

### **c) Why worker-ownership? (or Impetus for Development)**

The decades-long debate about the cost-effectiveness of nursing home care compared to home care ignores a key point: the costs of both community-based and institutional long-term care are predicted on a poorly-paid, poorly-benefited, and poorly-trained labour force. (Kane, as cited in Wilner & Wyatt, 1998, p. 6)

CHCA was developed as part of Independence Care Alliance's Replication Program. This program is in place to develop Community Economic Development businesses as worker co-operatives. The Replication Program is aimed at sectors, which fit the needs and aims of people with limited formal education and job experience, one of which is the home care industry.

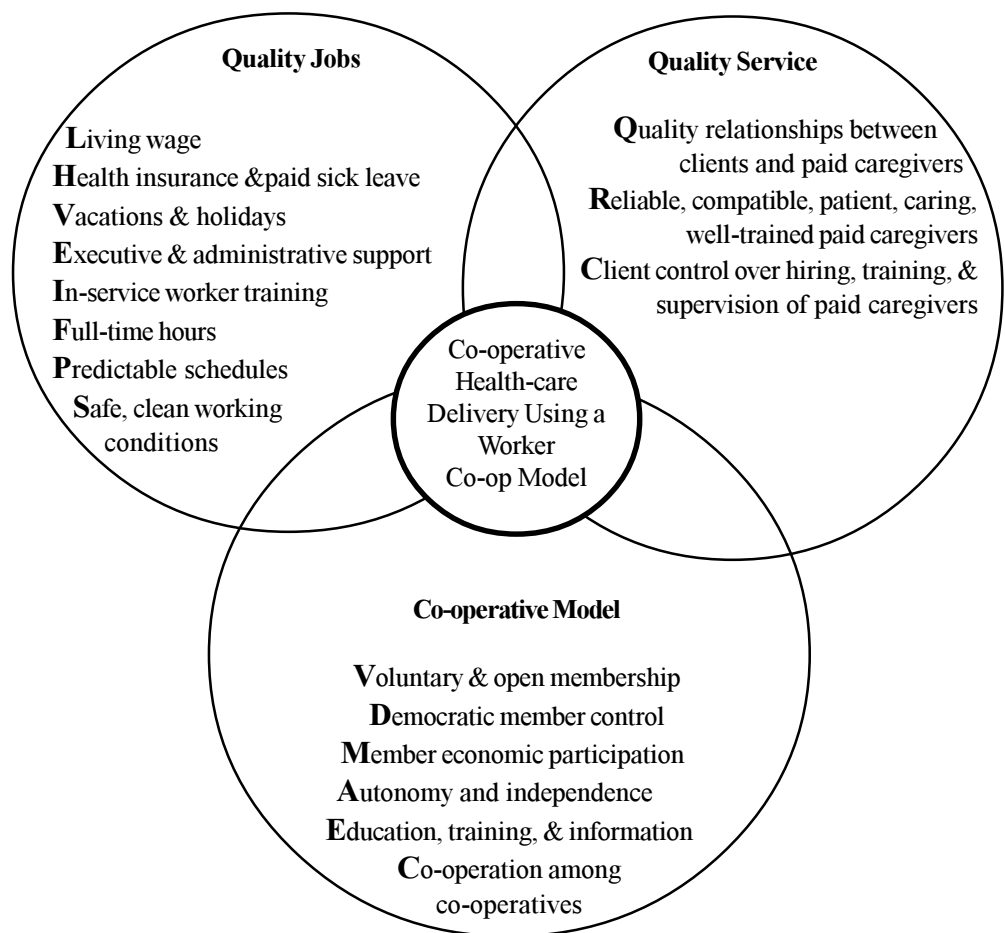
Cooperative Home Care Associates was developed to meet several gaps in the home care industry. Neither industry leaders nor accrediting bodies in the United States have set standards for wage and benefit levels or for percentages of government reimbursed rates that should be passed directly to labour costs. Most home health care workers though working, are poor, living without the support of employee-sponsored health insurance, pensions, or other benefits that would enhance their financial security. Home health care jobs carry the burdens of a shorter work week, less scheduled work, uncompensated travel time between clients, and a significant vulnerability to cutbacks in provincial and federal funding programs (Wilner & Wyatt, 1998). Home health care workers have had high turnover rates in certain segments of the industry due to this combination of poor salaries and benefits, poor working conditions, lack of adequate training support and supervision, not to mention a lack of opportunities for advancement (Wilner & Wyatt, 1998).

These work-related issues translate to quality of life concerns for people

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receiving home care/support, as low worker continuity and inflexible service provision create a health care service that is incompatible with the goal of full community participation for most seniors and people with disabilities.

### d) Vision: Quality Jobs = Quality Service



The founders and senior staff of CHCA are very clear about what community means to them and how a supportive workplace community fits in with their larger political visions. The four founders of CHCA are Rick Surpin, the moving force behind CHCA and its president almost since inception; Peggy Powell, who came on board six months after CHCA started and is now the executive administrator of the Training Institute, Kathleen Perez who joined

shortly after Peggy Powell, and Christine Archambault who joined the company in 1994 as Director of Nursing (Brecher & Glasser, 1998). Their collective vision was one that understood the tensions and richness of cross-cultural life, what it meant to be on the economic margins of society, and the importance of finding and forming a community. According to Surpin:

The vision was all about democracy and community, that what you could do at the community level was create a democratic institution that was participatory, but that participatory didn't mean collectivist so much as it meant that everybody could have a voice and come to decisions and that you could have control over your resources and you wanted to get more resources into poor communities. Build on a sense of community that was multiethnic and create institutions that would support that and programs that would support that and use resources in a much more creative way. (as cited in Brecher & Glasser, 1998, p. 13)

**RECALL:**

- Who defined the goals of CHCA?
- Is locating this power important to co-operative development?

This vision eventually lead CHCA to branch out beyond focusing on the creation of quality jobs internally into developing a service defined and controlled by consumers of home care. In January 2000 Independence Care Systems was founded, a nonprofit organisation committed to assisting people with disabilities to live independently. ICS is an alliance between the paraprofessional workers of CHCA and their managers/advocates and people with physical disabilities and their leaders/advocates.

The tactical objectives of CHCA are three fold: designing a 'good job' (focus: full-time positions, a higher starting wage, worker ownership), working toward long-range improvements in the industry, and creation of a model company (Dawson & Kreiner, 1993). CHCA is built on the premise that a high quality of service is directly linked to the perceived quality of the job of a paraprofessional. CHCA pays higher wages than its local competitors; offers health insurance and paid sick leave, vacations and holidays; provides at least twice the federally mandated amount of training; and offers extensive

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support and in-service training to its workforce. The result is that CHCA's home health aides have a turnover rate of 18%, less than half the industry norm (Wilner & Wyatt, 1998).

### RECALL:

· How was defining job and service quality a component of the CHCA development process?

CHCA endeavors to support consumer-members as the primary managers of their own care, treat everyone with respect and honesty, listen and respond to each other, value individual diversity, and develop confident, articulate, and skilled people. On a macro level, CHCA aims to be a national model for paraprofessional home care services, for which they have been the subject of a great deal of critical acclaim (Surpin, 2000). They are the recipients of the 1992 "Business Enterprise Award" from the Business Enterprise Trust for social responsibility in business, the 1993 "Brookdale Award for Best Practice in Human Resources and Aging" from the Brookdale Centre on Aging and the American Society on Aging, and the "1997 Corporate Conscience Award" for employee relations from The Council on Economic Priorities (Surpin & Dawson, 2000).

### e) Method of Development

One of the methods used by CHCA developers to discover the key characteristics of and criteria for job satisfaction was to define job and service quality from the perspective of both the workers (caregivers) and consumers. For consumers, the quality of the relationship with their paid caregivers determines how they assess the quality of care they receive (Wilner & Wyatt, 1998). Consumers want aides who are reliable, compatible, trustworthy, patient, caring, well trained, able to speak the consumer's language, and willing to do what the client would like, within reason (Wilner & Wyatt, 1998). Clients participating in consumer-directed programs want to hire, train, supervise, and dismiss their own home care aides. Many people feel that personal assistants whom they hire directly deliver a higher quality of service, which better matches their needs, than that provided by aides who are assigned by an agency; they also feel that these workers have higher retention rates.

The caregivers' defined job satisfaction in terms of their own ability to deliver high-quality care to the people to whom they were serving. Many caregivers described considerable satisfaction at being able to take care of people who need them and requested more hours of work and more predictable schedules in order to be able to develop good relationships with clients. Some barriers to job satisfaction included dissatisfaction with pay, benefits, and opportunities for advancement, too much work to do in too short of time, and feeling undervalued by superiors. Caregivers expressed a need for more recognition and support, as well as safe, clean working conditions (Wilner & Wyatt, 1998). Thus, CHCA developers identified a connection between caregiver job satisfaction and user satisfaction with the level and quality of service delivered.

For a breakdown of the development milestones of CHCA please look to Appendix One, which schematically outlines many of the key steps along the road to creating this successful co-operative.

Employees may choose to become members, or not, after successfully finishing a new-hire training program, for which they are reimbursed for expenses. CHCA developed their own training program in 1987, which, although chronically under-financed, was identified as a key component of the co-operative. Kathleen Perez described the importance of training: "From the beginning we saw education as, we're doing this because we want to create democracy, and we want a workforce that is always learning, and participates in its own learning and its own development" (as cited in Brecher & Glasser, 1998, p. 38). The training program was imaginatively constructed. There are two particularly interesting features: the use of home health assistants as assistant teachers, thereby providing trainees with teachers who are their cultural and vocational peers; and the way the program was organised within the framework of adult education methods, emphasising content, social skills, as well as technical mastery (Brecher & Glasser, 1998, p. 40). The training program is overseen by the director of nursing, Christine Archambault. Typically, the candidates selected for training are women with already highly-

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developed organisational and coping skills. Peggy Powell, the executive administrator of the Training Institute, indicated that CHCA's ability to train a broader population depends upon sources of funding and the company's need for growth (as cited in Brecher & Glasser, 1998).

Upon completion of the in-house training, home health assistants are hired on probationary status for three months and paid the firm's starting wage. Upon successful completion of the probation period, new employees are eligible to buy a member's share, at a cost of \$1000, which may be purchased over five years through a payroll deduction plan. Once the first \$50 is paid, individuals become full members with voting rights (Adams et al., 1993). In running the company, members arrange annual elections for the board of directors, at which only members may vote. To foster political participation within the firm as well as responsibility on the job, CHCA managers encourage paraprofessionals to get to know each other. Surpin describes this inclusive, 'people-growing' atmosphere as a process through which people gain the confidence to narrow the gap between managers and workers. Surpin said; "Most workers are afraid to offer suggestions about ways to improve their jobs, or to complain about the management when they first join the firm. Many have low self-esteem, particularly about 'running a business.' Through after-hour socials, or structured small group discussions, most soon learn that they can accomplish goals or differ fearlessly with managers. Many emerging leaders are a result of informal peer learning" (as cited in Adams et al., 1993, p. 15). This family-like atmosphere is one of the key characteristics of CHCA that sets it apart from a non-co-operative organisation – people have the opportunity, and are expected, to advocate for themselves and develop their skills.

### **f) Innovations in the Industry**

While it would be difficult to point to a specific aspect in the CHCA workplace culture, which has dictated its success, several home health aide

innovations have set a positive example for the industry.

In 1991 CHCA sponsored the creation of the Paraprofessional Healthcare Institute (PHI), a nonprofit organisation, to develop new programs and conduct policy analysis consistent with CHCA's "Quality Jobs/Quality Care" mission (Surpin & Dawson, 2000). PHI and CHCA are now sponsoring the creation of Independence Care System Inc. to develop a co-ordinated, interdisciplinary system of care for adults with disabilities in New York City. CHCA has also successfully demonstrated, over 15 years of operations, that the provision of paraprofessional service can be a full time job, with an average of 70% of its workforce employed full-time on a regular basis. Original training programs have supported the governing philosophy of CHCA (that the co-operative should be collaborative and foster personal growth, while still remaining financially viable), provided career advancement opportunities, contributed to a feeling of unity in the company, and implemented wage differentials for trained workers serving special needs clients (Dawson & Kreiner, 1993). Most importantly, these innovations are valuable to both clients and employees: the annual employee turnover rate is far below the industry average (in 1993 it was 11%, half of which was accounted for by involuntary discharge, in contrast to a then industry average of 45 – 60%), and all of CHCA's contractors have acknowledged a significantly lower level of complaints associated with CHCA's performance than with other home health care agencies in New York (Dawson & Kreiner, 1993).

CHCA has also led to the establishment of Independence Care System, Inc (ICS). ICS is a nonprofit subsidiary of the Paraprofessional Healthcare Institute (PHI), a nine-year-old independent nonprofit organisation affiliated with CHCA. ICS was started in 1998 on the premise that, if adults with physical disabilities and chronic illnesses had access to an organisation that could support them in planning and managing their own health care and social supports and in which they could participate in the governance, they would have considerably higher quality and co-ordinated care than is generally available from other organisations (R. Surpin, personal communication, July

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RECALL:

- How do language, power and partnerships interconnect in the development of CHCA?

24, & September 13, 2000). Both organisations strive to be the best in their respective fields and to be national model for managed long-term care for individuals with complex needs.

ICS was devised to address certain issues apparent to those involved in CHCA that have a great impact on the perceived quality of home care service, and therefore have an impact on the jobs of CHCA home support workers. Fragmentation of the services used by people with disabilities in the fee-for-service health care system is a barrier to enjoying a high quality of care and life for people with disabilities. Fragmentation means that people must go to one location for one type of service, another for another type, and so on resulting in an immense amount of time spent dealing with health maintenance. For those people living with disabilities, this work often limits, or even prohibits, their involvement in other areas of the social economy. This notion that health care systems must be flexible is important in broadening the impact of the “good jobs/good care” model of paraprofessional home care, which CHCA is striving toward. Similarly, the mobility needs of severely disabled adults have often been ignored in this system. It is often difficult to secure a transportation service that consistently arrives on time, that is flexible in the amount of time required to make a reservation, and that is affordable.

The goal of ICS is therefore to enable people with disabilities of all ages to remain at home, or in the least restrictive setting possible, by integrating the full range of primary care, acute care, and home and community-based services in a comprehensive, flexible manner (Surpin & Dawson, 2000).

ICS grew out of the mission and organisational culture of CHCA, and although CHCA is primarily worker-oriented, both organisations share the same values and beliefs:

- create quality jobs, especially for front-line workers, as a prerequisite for quality care;
- support consumer-members as the primary managers of their own care;

- treat everyone with respect and honesty, and especially listen and respond to each other;
- value individual diversity;
- develop people. (Surpin, 2000, p. 3)

ICS, which began operations in January 2000, is the first managed long-term care program in New York State designed expressly to meet the needs of people with disabilities. The other existing and planned programs focus on seniors.

### **g) Lessons Learned**

Part of the value of co-operative development is the challenges faced along the way. These obstacles, while daunting and perhaps even insurmountable, when documented, can help facilitate the development process for people wishing to follow their example. The lessons learned by those involved in Cooperative Home Care Associates, are summarised by Dawson and Kreiner in *Cooperative Home Care Associates: History and Lessons* (1993) in four categories:

1. enterprise development
2. creation of a democratic firm
3. corporate ‘innovation laboratory’
4. policy ramifications of being a yardstick corporation.

Some aspects of CHCA’s development surprised the co-operative’s founders. For example, they noted that development is a lengthy and uneven process in which careful planning, although essential, provides no guarantee of success. Similarly, as the founders had experience in starting up businesses but not co-operatives specifically, they realised that growth in successful community-based businesses constitutes a different set of challenges than capitalist businesses (Dawson & Kreiner, 1993).

With respect to the creation of a democratic firm, in selecting management for CHCA, the founders had difficulty in locating people with a

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workable mix between experience in the home care industry and compatibility with co-operative principles. The core business strategy of CHCA demanded

### RECALL:

- Does it make sense that belief systems be explored by all of those who will play a role in co-operative development as a part of the development process? What would such a philosophical discussion contribute to CHCA's development effort?

a dual focus: successful management had to deal with the demands of the existing conventional market as well as wants and needs of worker-owners. Core business decisions as well as day-to-day practice must be consistent with “employee centered” workplace (Dawson & Kreiner, 1993). The value of creating an empowering workplace culture, which was really the essence of the co-operative itself, made selecting an appropriate executive director a recurring challenge.

As an innovation laboratory for quality and cost-effective health care, developers of CHCA have stressed emphatically that the most valuable lesson learned is that of the relationship between quality jobs and quality care and that home care work can be a full-time, satisfying job.

As a yardstick corporation, defined as a “private company whose accomplishments are respected and whose analysis is trusted by public regulatory agencies, health policy organizations, labour organizations, and the media” (Dawson & Kreiner, 1993, p. 1), CHCA works to change the behaviour of their contractors. CHCA leads the industry by example toward making home care provision a satisfying job. The strategy at CHCA was one of “best practices,” in which “they sought to convince their contractors and others in the industry that innovations in quality of jobs led directly to a higher quality of care, and yet at the same time were cost effective” (op.cit., p. 33). In leading by example, CHCA sought to influence the rest of the home care industry into conforming to the job standards set by CHCA. Interestingly, the state regulatory bureaucracy proved an impediment to circulating information about CHCA's innovations.

In an industry such as home care in which the state regulatory bureaucracy has such restrictive control, the quality of CHCA's “best practice” may not necessarily be rewarded. CHCA's developers found a way around the barrier of the state regulatory agency by organising key stakeholders to

improve regulatory and reimbursement environments at the state and city levels (Dawson & Kreiner, 1993). It was noted that the first and most important step toward achieving this was to communicate to the key actors that quality care is directly related to the provision of quality jobs (Dawson & Kreiner, 1993). Therefore, the importance of communicating the intent (social, ideological, moral) of co-operative developers, is one of the fundamental lessons that can be learned from Cooperative Home Care Associates.

### **h) Concluding Remarks**

Cooperative Home Care Associates is a unique business: it is a democratic (or co-operative) firm, setting a precedent which is being noted in New York and further afield, and it has been successful in an industry which appeared to be totally hostile to the developers' notions of 'good jobs.' For the developers of CHCA, a required part of the process of developing the co-operative was to define quality from the perspective of home health care workers. Once they had defined 'quality' and identified it as a goal of the co-operative, they had the task ahead of them of putting their philosophy into practice. Stemming from this goal of creating quality employment and building on the skills of people, CHCA has branched out into Independence Care Systems and has fostered the establishment of similar co-operatives in Boston and Connecticut. Practicing their vision demanded repeated articulation of the link between quality jobs and quality care, a major innovation in the home health care industry.

### 4.2 The Stockholm Cooperative for Independent Living

In 1984, after organizing the first Scandinavian conference on Independent Living, with Ed Roberts and Judy Heumann representing the American branch of the movement, I gathered a group of disabled persons who needed personal assistance services to found STIL, the Stockholm Cooperative for Independent Living in order to establish our very own services. The group was inspired by the principles of Independent Living: self-determination and “We are the experts!” In 1987 we managed to overcome massive resistance from some political parties, the labor unions, traditional service providers and the established disability organizations and started operations of our cooperative, first as a pilot project, since 1989 on a permanent basis. During the following years, as a result of our political and media work we managed to spread our message across the country: “We know best what we need. Those of us who want should get the means to run their own services, with better quality at the same cost.” (Ratzka, 1996, p. 9)

Co-operatives, as I have already discussed, are important in that they hold the potential to afford more control to consumers over publicly-funded health care. Additionally, and as discussed by Wendy Cocksedge (2001), by differentiating themselves from others in the industry, co-operatives are in a position to develop and promote not only a product, but also a concept and a value. The Stockholm Cooperative for Independent Living (STIL), is a demonstration of ingenuity and capability of people with disabilities in deliberate harmony with the aims of the Independent Living movement.

As their name suggests, STIL is centered in the philosophy of the Independent Living Movement. This international civil rights movement of people with disabilities has the aim of gaining control over the services that are necessary for participating in society on equal terms with (temporarily) able-bodied people. STIL’s objective is to increase the number of personal

assistance alternatives for people with disabilities. Their hypothesis is that a larger extent of consumer involvement will translate to a greater amount of consumer satisfaction and productivity. In the same way that Cooperative Home Care Associates stresses the characteristics of a 'good job,' STIL places primary importance on the qualitative aspects of attendant care. These include power and control, self-determination, self-esteem, and quality of life for the users of personal assistance. The key divergence between STIL's governing values and those of conventional models of service delivery exists in the difference between being treated as an object and acting as a subject.

In *Power: A Radical View* (1974), Steven Lukes defines the concept of power by saying that "*A* exercises power over *B* when *A* affects *B* in a manner contrary to *B*'s interests" (p. 34). He maintains that, according to a three-dimensional view of power, [people's] wants [i.e. interests] may themselves be a product of a system which works against their interests, and, in such cases, relates the latter to what they should want and prefer, were they able to make the choice. In developing STIL, people with disabilities not only worked according to an idea of what they should want, given the opportunity, they extended that vision into a working business whose message has been spread around the world.

### **a) STIL – Who, What, Where**

Dr. Adolf Ratzka, chairperson and founder of STIL, traced the origins of the co-operative back to an Independent Living seminar organised in 1983. The seminar was intended to introduce the approach of the Independent Living movement to Sweden. At that time, Sweden fostered personal assistance programs characterised by a high degree of professionalisation and a low level of consumer input (Ratzka, 1986). As a result of this Independent Living seminar, Stockholm's Independent Living Group was formed in December 1983, and from that group the STIL pilot project started in 1984. According to the Independent Living Movement, with the right circumstances, all people can increase their capacity for self-direction. STIL was founded with the

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intent to increase the number of options and amount of control available to users of personal assistance.

STIL is now an established co-operative company with an annual turnover equivalent to USD 17 million. Presently the co-operative has 230 members and is growing every month. In 1998, STIL produced 770,000 service hours, allocating 900 pay cheques to members' personal assistants each month. The director of STIL and over half of the office staff have disabilities. All board members are personal assistance users (Ratzka, 2000b). STIL's membership consists of persons with extensive and often multiple disabilities who need personal assistance in their daily lives. STIL trains members to become employers of their personal assistants. The co-operative provides a mandatory "boss course" taught by members of the co-operative who have long personal experience in employing assistants, as well as periodic evening peer support sessions with the facilitation of experienced personal assistance users. STIL's aim is to empower members by providing the practical means for self-determination, independence, and integrity in their daily lives.

### RECALL:

· How do language, power, and partnerships interconnect in the development of STIL?

This includes providing role models, sharing experiences, insights, and mutual support. Most importantly, STIL aims for user control through economic independence.

STIL is a not-for-profit member organisation; any operating surplus is put into improving services and spreading the STIL model of personal assistance schemes, based on direct payment to the individual user, to other locations (A. Ratzka, personal communication, June 26, & September 13, 2000).

### b) Target Industry

Many people with disabilities argue that if the design of personal assistance programs is left to service providers, systems are likely to result that conform to the needs of the agency but not necessarily the consumer. Similarly many people with disabilities feel that government agencies, when

left alone, tend to develop a single solution to satisfy all needs. From an administrative point of view, a single service delivery system is more convenient than one more flexible to individual variations. Yet people with disabilities are unique individuals with individual physical and emotional needs, personal resources, and life circumstances that will vary over time. Developers of STIL believe that consumers need to have alternatives in order to be able to live according to individual variations (Ratzka, 1986).

Personal assistance reform appears to be an obvious choice for people with disabilities and/or people who understand the values of independent living: if users of the service are able to control the circumstances of its allocation, greater autonomy and ability to live independently will ensue. Adolf Ratzka describes the propensity for people with disabilities to grasp this concept of independent living in the following prelude to his 1993 article, *The User Cooperative Model in Personal Assistance: The Example of STIL, The Stockholm Cooperative for Independent Living*:

Personal assistance, like no other service, illustrates the key elements of Independent Living. People who need personal assistance have always been made dependent on others for the most basic needs of life such as eating or using the toilet. Given this physical dependency, the consequent conclusion was to consider us as dependent on others emotionally and intellectually as well. If you cannot pull up your pants like a small child, you may be treated like a small child in other areas as well. It is no surprise that it is those people who need personal

Academic research has been structured along the same lines, with researchers traditionally doing research 'on' people. In their work *Experience, Research, Social Change: Methods from the Margins*, Kirby and McKenna (1989) focus on how differences in power have resulted in a monopoly on knowledge production. "Most of us have not had the opportunity to research, to create knowledge which is rooted in and representative of our experience. We have been excluded from participating in, describing and analyzing our own understanding of reality" (p. 16). Kirby and McKenna, in contributing to the methodology of research from the margins, strive toward research not on people, but by, for, and with them.

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assistance who most easily grasp the Independent Living philosophy.  
(p. 36)

Co-operatives in the Scandinavian tradition share a democratic form of ownership (one person, one share, one vote), and also a strong element of membership education and commitment. The fit between user-directed personal assistance and co-operation was logical. According to Ratzka, the co-operative form of doing business presented itself additionally as “a convenient way of alleviating the political opposition on the part of the Social Democratic party, the Communist Party, and the Union of Municipal Workers, which saw STIL as a move towards privatisation and considered Ratzka and the other pilot project members as unable to understand the consequences of their actions” (Personal communication, June 26, & September 13, 2000). Personal assistance was a logical choice for co-operative development in that it is one of the keys to independent living for people with disabilities.

### **c) Impetus for Organisation**

Members do not see themselves as helpless hospitalized patients who need protection from private profiteers, but as healthy, self-directed individuals living in their own homes, pursuing an active life, and knowing what is in their best interest.  
(Ratzka, 1986, p. 1)

Social policy has traditionally been the domain of service providers, as opposed to consumers. Even if consumer groups sometimes succeed in lobbying for a reform, they rarely have the possibility of getting involved in the actual design of policy instruments. Due to an alleged lack of administrative experience or formal qualifications, it is common to leave the work of developing appropriate health care for marginalised people to administrators, social workers, medical doctors, or lawyers (Ratzka, 1986). The expertise of consumers is often under-valued, even though consumers have the most intimate experience of how personal assistance influences their lives.

The development of STIL is seen mainly as a protest against cluster housing or other institutional solutions to the ‘problem’ of adults with disabilities. STIL’s membership consists of individuals with extensive physical and/or developmental disabilities who, when reliant upon traditionally structured personal assistance, often face very limited choices in life (Ratzka, 1986). The home care services provided by local governments in Sweden before the advent of STIL were highly bureaucratic, unresponsive to user needs, and totally controlled by service providers (Ratzka, 1993). Some impacts on users of compartmentalisation (or systemic disintegration) of Personal Assistance services include:

- agencies involved in service provision have their own eligibility criteria and periodic eligibility checks, often answering phone calls only during certain hours of the day;
- services have to be ordered at least one and sometimes several work days in advance, which forces the individual consumer to spend a large number of hours each month handling these contacts;
- consumers that don’t have the time or energy required for these administrative tasks or don’t have the capability or possibility to plan their life so far in advance (e.g. for health reasons) cannot utilise the services to the degree they would need them;
- consumers are often dependent on several services, however with each additional one used, the probability of delays or breakdowns in the total system increases rapidly as problems can arise in any link of the chain. (Ratzka, 1986)

### RECALL:

- Who has had the power in discussions between people in different social positions to define health care service delivery? Who has control over the development of STIL? Is locating and negotiating this power important to the co-operative movement?

Thus, the traditional service provider-centered system has rendered consumers dependent on and vulnerable to the smooth interaction of services provided by several agencies. The system’s insensitivity to user needs has bred a sense of alienation and powerlessness in consumers.

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An acute desire to avoid institutionalisation was also impetus for the development of STIL. Institutions tend to dissipate the personality and individual agency of those living in them and, in the same way, systems that are insensitive to the needs of the users tend to devalue user expertise. For example, the concept of ‘hospitalism’ has been put forward by people living in institutions (or those wishing to stay out of them): staff often consider the patients as less capable than do the patients, leading to a rapid deterioration in patient confidence, especially among older people. Self-confidence is a quality highly valued by most people and could even be considered essential to be able to live in accordance with the philosophy of independent living. Assistance in and outside the home is the key to community participation and is the most important prerequisite for keeping people out of institutions. Therefore, personal assistance needed to be reformed to increase sensitivity

to user direction and to increase the quality of life for seniors and people with disabilities.

### RECALL:

- Is the use of language important to STIL’s development?
- According to STIL’s framework, is there a functional difference between home care, home support, and personal assistance services, or is the distinction simply one of terminology?

The Independent Living movement believes consumers are the experts in deciding their health care requirements. It follows that personal assistance should be consumer directed. In fact, many consumers of home health care services contend that it would be a wiser investment to train the user of services rather than the service provider, especially in light of the 30%

per year turnover rate among assistants in the late 1980s (Ratzka, 1986). Members of STIL claim that, “the less institutional work experience and health care-related training assistants have the easier it is for the consumer to direct his or her assistants” (Ratzka, 1986, p. 3). Essentially, the issue in using assistants is not only that people with disabilities often need help in performing the chores that they are unable to do, but developers of STIL insist that the choice as to how to spend their energies should be theirs. The development of STIL occurred to increase and safeguard choice in the lives of co-operative members.

### **d) Vision**

According to the philosophy of STIL, people with disabilities, despite their common need for personal assistance, are individuals with different personalities and social and economic background who have the same right to find their own way of living as their non-disabled peers (Ratzka, 1986). The right to this flexibility requires that housing and services are not linked into one bundle as in cluster housing and that central state personal assistance allowances are directly paid to the consumers to enable them to purchase the services from whomever they choose (Ratzka, 1986). The vision of STIL is that local governments directly pay the user the same amount of money that his or her services would cost if provided by the government.

Choice is the key to independent living; the best guarantor of choice in a system is consumer control. The term “personal assistance” is suggested for use by developers and members of STIL because it is believed to contribute to a self-directed, independent, and capable image of consumers (Ratzka, 1986). Consumer controlled personal assistance must be flexible. This means that each consumer has to be able to exercise precisely that level of personal responsibility over the service and perform those administrative tasks that he/she feels comfortable with at a given point in time. Also, moving from one level of responsibility to another has to be possible in either direction (up or down) with minimal bureaucratic effort (Ratzka, 1986).

### **e) Objectives**

The overall objective of STIL is to increase the number of personal assistance alternatives for people with disabilities. This includes a specific focus on the qualitative aspects of attendant care, targeting power and control, self-determination, self-esteem, and quality of life for users of personal assistance services. Quality of life is the driving force. In developing STIL, users of personal assistance were quick to distinguish between quantity and quality in service delivery:

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- between the amount of hours and way they are delivered;
- between the level of material means provided by the public and the level of control exercised by individual consumer over how these resources are to be used;
- between being treated as an object and acting as a subject. (Ratzka, 1986)

### **f) Method of Development of STIL**

In order to put the philosophy of STIL into practice, systems for the support, training, and protection of consumers were developed to aid users at each point along the path to self-determination. STIL is based on a concept of peer counseling, where new members receive their training from established personal assistant directors. Tasks involved in the administration of personal assistants include:

- negotiating with the sponsoring government agency for necessary funds;
- recruiting workers (advertising, interviewing, screening, formulating a contract, hiring, firing);
- formulating consumer needs as to number of hours and type of assistants, what skills are required from the workers, and how the work is to be done;
- setting up routines for payment of wages, bookkeeping, and accounting to the funding agency;
- legal responsibilities of employers such as tax withholding, payment of employer's fees, fringe benefits, observation of legal aspects which regulate the employer-employee relationship. (Ratzka, 1986)

In STIL's user co-operative model the individual user is solely responsible for recruiting. STIL has no common assistant pool since this would limit the individual user's discretion. The individual user can advertise anywhere and in any way to attain personal assistants, for example, placing ads or by word of mouth. Each member is responsible for the training, scheduling, supervision, motivation, and re-training of his/her assistants according to

his/her individual needs. Consumers either use experienced assistants to help in training new ones or, as recommended by STIL, train each assistant himself/herself for full control over the training. STIL is forwarded potential members partly through local Swedish governments in charge of informing people who might be eligible for personal assistance payments. Disability organisations also inform their members about the program and their rights. Additionally, STIL conducts courses, distributes literature and employs staff to answer questions during office hours. STIL members must participate in in-depth training in order to take on personal assistants:

In STIL's user cooperative model membership in the cooperative and the scheme is awarded only to graduates of the "supervisor course" which prepares the user for the task of becoming supervisor of his/her assistants. Course consists of 10 evenings covering such topics as How to use personal assistance to reach life goals; How to assess one's needs; How to apply and argue for the payment; How to recruit, train, supervise, motivate, terminate assistants; the necessary paperwork; the union contract, assistants' employment conditions; and labor laws pertaining to safety and health in the workplace. STIL members also have access to support from staff consisting of experienced personal assistance users. We have also had a "buddy" system where we have tried to link new and inexperienced members with members with long experience in running their own assistance. (Ratzka, 1998, 2.3.3)

STIL is also accessible for people with developmental disabilities. In most cases, their legal representative - most often a relative - will take on the function of recruiting, training, and supervising assistants. In some cases, where this support has been weak or lacking, STIL has tried to assist the respective member by appointing a "deputy supervisor" with the member's consent. In turn, the deputy supervisor is supervised by STIL's office staff (Ratzka, 1998).

STIL was therefore developed to support and empower users of

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personal assistants, with attention to key elements such as training, mentoring, advocating, and like-minded leadership.

### **g) Orientation/Workplace Culture**

STIL was developed to alleviate the sense of frustration and dissatisfaction among many people with disabilities who were experiencing systemic dependence (Ratzka, 1986). The hypothesis in developing STIL was in line with the stipulations of the Independent Living Movement: the larger the extent of consumer involvement, the greater the consumer satisfaction and productivity, in turn enabling users to be more active. The workplace culture of STIL is based on the theory that “control over a service which is central to one’s daily life and the opportunity of bringing about changes through one’s own efforts with the risk of failure and the rewards for succeeding are bound to decrease alienation and might well lead to a better self-esteem which can carry over to other spheres of one’s life” (Ratzka, 1986, p. 5).

STIL is also concerned with measuring quality in service provision. Consumer-oriented quality criteria measure the following indicators:

- turnover rates among workers;
- reliability and punctuality of assistants;
- range of tasks which may be carried out by assistants;
- intensity of service (i.e. maximum amount of hours granted and at what times);
- geographical mobility permitted by the service (at home, work site, outside the community, abroad);
- consumer’s control over who will carry out the work;
- flexibility and consumer control in scheduling assistants;
- time spent by the consumer in administration of the service. (Ratzka, 1986)

Since the aim of independent living is full emancipation and participation, people

with disabilities seek parallel degrees of freedom in all aspects of their lives. These include education, employment, transportation, housing, politics, the economy, and the social and cultural life of their communities. Accessible, flexible, and user-directed personal assistance is held to be the first step in liberating people with disabilities and the foundation upon which all other freedoms rest. The most important stipulation in the workplace culture of STIL is that comparisons are necessary between citizens with disabilities and their non-disabled peers. Developers of STIL demand that this goal of empowerment of people with disabilities be used as a benchmark against which all activities of the co-operative are measured.

### **h) Innovations in the Industry**

STIL became the model for the Swedish Government's Personal Assistance Reform of 1994. Passed on May 27, 1993, the Act concerning Support and Service for Persons with Certain Functional Impairments entitles anyone covered by Section 1 to receive benefits if they:

1. have not reached the age of 65, and
2. need personal assistance for daily life during an average of more than 20 hours a week. (Konberg, 1994)

The legislation enables assistance users to receive Direct Payments without belonging to a user co-operative. The principle of Direct Payments is explained in the following statement:

Institutions, whether stationary or mobile, are expensive to run. And yet the quality of life for the users is low. The solution, obvious to most disabled persons, is to try to get money instead of services. We call this "direct payments." With the same amount most users can achieve a better quality of life, either by purchasing the services they need in the market or by organizing their own services. Services in kind control us, direct payments empower us. With services in kind, we are the passive objects and have to take what we get. With money in our hands, we can buy services from the provider of our choice. (Ratzka, 1998, 3)

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That the Swedish legislature recognised the significance of direct payments to the quality of lives of people using personal assistant services is a major success. In the opinion of Dr. Adolf Ratzka, the Executive Director of STIL, “the cooperative form of doing business with Direct Payments for personal assistance was ... the only way of introducing Direct Payments to be handed over to a population which Swedish society considered as helpless and dependent” (Personal communication, June 26, & September 13, 2000). Thus, not only did the developers of STIL demonstrate their capabilities to themselves, they also had a large enough impact in society to affect a change in legislation to accommodate the philosophy of Independent Living. STIL has made a very important contribution to the paradigm shift from disabled people as patients to citizens (A. Ratzka, personal communication, June 26, & September 13, 2000).

Several other innovative features of STIL are outlined on the STIL homepage. The description of STIL found here states that its work is characterised by training and empowering disabled persons in a mutual fashion without traditional “experts”; demonstrating to other persons with disabilities and to the public at large that personal assistance users can be good employers, administrators and organisers; development of a methodology for empowerment through peer training and support; and systematically utilising role modeling as an integral and main ingredient in all its training and public activities (A. Ratzka, personal communication, June 26, & September 13, 2000).

In traditional social work, people with disabilities have been placed at the receiving end of ‘help.’ They are the students, trainees or recipients of aid and support, with any initiative and active role typically taken by non-disabled persons. STIL, in its Peer Training and Support Scheme, has taken the opposite stance: they maximise the utilisation of experiences and skills of persons with disabilities. This recognition of user expertise is a very innovative approach to health care and social service delivery.

The case study of STIL is well known among the disability community, particularly those involved with the Independent Living movement. STIL was the model for the establishment of the New Jersey Personal Assistant Cooperative Services, Incorporated, founded in 1996. STIL has also been cited as the inspiration for the development of Independence Care Systems, the first managed long-term care program in New York State designed expressly to meet the needs of people with disabilities.

### **i) Lessons Learned**

As to the limitations of the STIL model, we are still not finished with the job of building it. Its quality will always depend on the members. There has to be a critical mass of members with skills, motivation and solidarity. (Ratzka, 1993)

Many features of the user co-operative model of STIL depend on the wisdom and enthusiasm of the leaders. According to STIL bylaws, the board must be 100% assistance-users. Developers of STIL fear that their scheme will deteriorate if not enough capable people have the time and energy to serve on the board (Ratzka, personal communication, June 26, & September 13, 2000). Also, they have identified that it has been difficult to find personal assistance users for qualified staff positions. The availability of peer support, a key component of STIL, depends on motivated members who will work in this field. The co-operative is vulnerable because it delegates so much responsibility to individual members. If some members do not live up to their duties or, for example, treat assistants unfairly, STIL'S reputation would suffer and it would risk action from labor unions (not to mention contradict their overall goals of quality of life and empowerment).

Developers of STIL have also indicated that 'good buddies' and deputy supervisors are very hard to find. Ratzka has stated that, given STIL's rapid growth, the need for buddies, deputy supervisors, and peer support staff far

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exceeds the number of members who are willing to work with these issues. Also, once someone has become a member, STIL cannot force them to seek help in managing their affairs, since the co-operative respects each member's right to run their own lives without interference from others (Ratzka, 1998). This leadership element is one aspect of the working of STIL that would have been hard to predict in advance. STIL must also contend with limitations imposed on the co-operative by the law and Social Insurance. Co-operative members have been demonstrating and lobbying to improve the current system and fend off cutbacks.

Another obstacle faced by developers of STIL has been the political battle over economic independence. Local governments were reluctant to relinquish control of the funds used to cover personal assistant services. As a result, members of STIL were forced to fight over the average price per hour that the co-operative would receive for each hour of personal assistance produced (Ratzka, 1993). Developers of STIL considered it imperative that members of the co-operative, and the co-operative itself, have "control through economic independence" (Ratzka, 1993, p. 38). In order to obtain economic independence and remain competitive in the price and quality of service provided, developers of STIL insisted that an average price per hour be negotiated for each hour of personal assistance produced. In this respect, the co-operative wanted to be treated like any other enterprise in business dealings with the government (Ratzka, 1993):

One of the biggest obstacles in setting up STIL as a permanent business was the demand of local government officials that our scheme be integrated into the regular government administration, i.e., as a branch of the social services office. They offered STIL free office space and the salary of 1 or 2 administrative staff in addition to paying us the direct labor costs of our personal assistants. We were not tempted, since we realized that by controlling our administrative expenses and office space, the local government would be able to also control our activities, our growth, and the direction of our movement. ... Like any other company we wanted to run our business

on income from sales and not on government grants. Grants can be adjusted up or down depending on fiscal priorities and how politically expedient a given activity is for the establishment. (Ratzka, 1993, p. 38)

After an arduous battle in which STIL estimated the local governments' costs for the personal assistance services, developers of the co-operative convinced politicians to pay this amount to STIL. Thus, through attaching health care payments to the users, STIL attained control through economic independence.

### **j) Concluding Remarks**

The contention, implied by some social services professionals, that many people with disabilities do not have the ability to manage their personal assistance was a barrier to the development of STIL. Through the actions of this co-operative, and in conjunction with the Independent Living movement, people with disabilities are changing the way disability is thought of and correspondingly how health care service is organised. Quality of life was factored in by developers as one of the components of health care for users of home health care. By articulating the meaning and importance of personal assistance, STIL has paved the way for future co-operatives in this area of health care. STIL has had a very significant impact on the developers of the Personal Assistance Co-operative Society (PACS) in Victoria, British Columbia, who were impressed by the ideological message of STIL, enough to model PACS after STIL's lead.

### **5.0 Next Steps: Further Research and the Personal Assistance Co-operative Society**

5.1 How did I get here?

5.2 How did I do?

5.3 Next Steps: the Personal Assistance Co-operative Society (PACS)

a) Summary of Goals for PACS

b) Proposal for Future Co-operation

c) Concluding Remarks

#### **5.1 How did I get here?**

In January 2000, I began to work with Dr. Kari Krogh at the University of Victoria as a research assistant involved in a Participatory Action research project.<sup>9</sup> This video project, funded by the Social Sciences and Humanities Research Council of Canada, was a collaborative effort between the academic research and disability communities. Participants included Dr. Krogh, Faculty of Human and Social Development of the University of Victoria, and the Home Support Action Group (HSAG), a coalition of community groups and allies. The video that was produced is entitled *Beyond Four Walls. Disability, Work and Home Support Policy: Linking Research to Multi-Sector Action*. My role in *Beyond Four Walls* was to support the Home Support Action Group in any way they felt necessary. I have been taking minutes at bi-monthly meetings with HSAG, keeping a detailed log of the groups activities, attending lobbying meetings with policy makers, politicians, and regional health boards, co-coordinating a community forum for the launch of *Beyond Four Walls*, and performing various other tasks.

In the process of this work, particularly in meetings with policy makers, I became aware of the difference in understanding between HSAG (which consists predominantly of people with disabilities and advocates) and the people (often in positions of relative power) the group was lobbying. I have noticed that the difference in thinking between consumers and service

providers stalls efforts to address the home support crisis in the Capital Health region. I think about my earlier statement:

I hold that co-operative development is tied to the political worldviews of people working to start co-operatives, many of whom have not had the power to define public agenda in the past. In this respect, co-operative development is not theory, but action: it is about people mobilising to change the circumstances of their lives.

The Home Support Action Group is striving to stop the reduction of publicly-funded home support services in the Capital Health Region. In doing so, HSAG has had to focus one-third of their efforts on public education. People with disabilities rely on home support for basic assistance in activities of daily living, working, and participating in their communities. Without sufficient levels of home support, people with disabilities often cannot work and therefore cannot contribute economically, socially, or politically to our society (Krogh, 2000).<sup>10</sup> However, Canada's health care system is oriented around service providers who, by nature, have different needs than users of the system. Any changes to the system are in the hands of bureaucracies. To affect change, users must educate service providers and people working within the system, the majority of whom are non-disabled and non-users of home support, about both the nature of their needs and the reality of their lives. HSAG has hit a wall: the people with power to influence decision-making and funding allocation are the least equipped to determine what kinds of services are important to whom, and why.

When I started researching home care and home support co-operatives, I had a heightened awareness of the importance of ideology in discussions between people with different understandings of the world. I was immediately drawn to the language used by co-operative developers, noticing the different understanding and use of words by people 'on the ground' and people working higher up in the system. Language is tied to the history of knowledge creation and academic research done 'on' people. This makes it a significant process for marginalised people to begin to control. The process

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of claiming control and communicating this vision to both policy makers and prospective members demands a shift in the traditional conceptions of health care and social systems in general. I wondered if the co-operative model of home support delivery could provide my frustrated colleagues in HSAG with the opportunity to both define their needs and put that definition into practice.

### 5.2 How did I do?

My initial research objectives were to:

1. Discover how co-operative models of community economic development work to meet the needs of both the consumers and providers of home care/home support.
2. Consider the efficacy of available case studies, looking for opportunities to learn from the successes and obstacles faced by other co-operative development initiatives.
3. Reflect upon the need for such co-operatives in the Capital Health Region, Vancouver Island, British Columbia, and suggest a model for a home care/home support co-operative.

I wanted to learn how co-operative models of community economic development work to meet the needs of consumers and providers of home health care. Co-operative organisations can provide a chance to act for those with a vision of how a system could be better organised to meet their needs. They also have the potential to empower marginalised people and communities by enabling people to support each other and work together on things that they could not accomplish alone. Through both of these avenues, co-operatives are able to change peoples' lives at the local level by giving them a chance to control something formerly out of their command. These features of the co-operative model make it well suited to the health care field.

Co-operatives also depend largely on the ingenuity and dedication of their leaders and members, a trait that can be both a help and a hindrance.

They are not well suited to people who do not wish to commit large amounts of energy to the thinking and organising of a company. Likewise, as they demand so much entrepreneurship from their developers, co-operatives can be limited by policy that is insensitive to the goals and worldviews of people working at the grassroots level.

The importance of communicating the intent (social, ideological, practical, political) of co-operative development is one of the fundamental lessons to be learned from this research project. Self-definition and self-help are among the founding principles of co-operative development. These characteristics make the co-operative model particularly well suited to home support. The founders and members of the co-operative are empowered to define the vision, goals, and day-to-day workings of the co-operative, a welcome opportunity in many cases. CHCA defined quality jobs according to caregivers in order to achieve quality service according to users; STIL started with the beliefs articulated in the philosophy of independent living and worked forward from there – any actions of the co-operative or reform in personal assistance had to uphold the right of people with disabilities to control and choose; any innovations in the home care industry in New York had to be with an understanding among the key actors that quality care is directly related to the provision of quality jobs.

This research has shown that a functional difference does exist between home care, home support, and personal assistance services. The Home Support Action Group in Victoria, British Columbia prefers the term home support over home care as it reflects a more holistic view of health and a service that is more than just personal care in the home. Cooperative Home Care Associates calls their service home care, carried out by paraprofessional health care workers. STIL insists on the use of personal assistance, claiming that any other term carries institutional connotations and does not clarify that the service must be tied to the person in order to support independent living. These are all real distinctions between very similar terms. The only way for us to uncover these differences is to ask the co-operative developers themselves

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why they chose to use particular terminology and what they mean by it. Outdated language carrying institutional connotations and/or a misunderstanding of disability or aging has no place in co-operative development. In this respect, belief systems are very important: members' beliefs will dictate members' ideas of success.

I think co-operative models of community economic development are a viable option to meet the needs of consumers and/or providers of home

### **Home Support Action Group – A Brief History**

The Home Support Action Group came together on November 1, 1999 in response to the continuing cutbacks and the 120 hour cap on service instituted by the Capital Health Region. Since that time, the Group's energies have been focussed on the following actions:

- A letter writing campaign targeting policy makers in the Federal and Provincial Ministries of Health, local, and Provincial MLAs to pressure the Minister of Health into re-evaluating Ministry policy and restoring funding for Home Support;
- The production of a video, "*Beyond Four Walls: Disability, work and home support policy: Linking research to multi-sector action*," illustrating some of the impacts of funding cuts to home support on the lives of people with disabilities;
- Meetings with CHR officials, including CEOs, directors, and program managers, to discuss stopping the cutbacks in Home Support, re-vamping the assessment tool, and creating a fair appeal mechanism;
- Formal and informal presentations to the CHR Board of Directors to gain public support and media coverage of the issues;
- Meetings and lobby campaigns with NDP leadership candidates, Liberal and NDP MLAs;
- Writing letters and articles in the Times Colonist protesting the CHR cuts and addressing discriminatory reporting by members of the Times Colonist staff;
- Meetings with lawyers to assess the possibility of issuing a challenge under the Canadian Charter of Rights and Freedoms (1982) re: portability of funding for home support for people with disabilities, and changes to CSIL contracts without the informed consent of CSIL clients;
- Efforts to form alliances with groups directly affected by reductions in Home Support, such as senior citizens and First Nations people with disabilities, or those who might have an interest in the issue and offer support such as unions, the Advisory Council on Women's Health, the Council of Canadians, Victoria Health Coalition, legal advocates, academics, and media representatives.

health care. The nature of co-operative development demands that people, with both mutual and diverse interests, work together in order to meet their goals. Language, power, and partnerships interconnect in the communication necessary to succeed in co-operative development. Paradoxically, although government programs have been set up to facilitate and support co-operative development, there are no such programs targeted to ease communication between government programs and representatives and community leaders and members. This seems like a logical recommendation to policy makers: we must work on the communication and conceptual aspects of co-operative development to make policy more flexible to the needs of co-operative entrepreneurs.

Reflecting upon the case studies, the key question addressed by CHCA was whether a profitable enterprise could be created within the constraints of the home health care industry that still significantly improved the quality of the home health paraprofessional's job. We have seen the results of their work in progress: CHCA's home health aides have a turnover rate of less than half the industry norm; all of CHCA's contractors have acknowledged a significantly lower level of complaints associated with CHCA's performance than with New York's for-profit agencies; and CHCA has successfully demonstrated, over 15 years of operations, that the provision of paraprofessional service can be a full time job, with an average of 70% of its workforce employed full-time on a regular basis. The CHCA example of changing the nature of a low status job is a legacy for future co-operative development. The principle of empowerment with which they conduct their business is both effective and admirable. I think, however, that the potential implications of organisations such as ICA parenting worker co-operatives merit further exploration: to what extent is the co-operative charity-based, and does it mean that the self-help principle of co-operatives is dependent on the guidance of larger community economic development organisations?

The objective of STIL is to increase the number of personal assistance alternatives for people with disabilities. Their hypothesis is that a larger extent

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of consumer involvement will translate to a greater amount of consumer satisfaction and productivity. Developers of STIL have frankly stated that the development of this co-operative has proven challenging, with a heavy political battle over funding and tiresome recruitment of competent peer trainers. However, to their immense credit, STIL became the model for the Swedish Government's Personal Assistance Reform of 1994. The legislation enables assistance users to receive Direct Payments without belonging to a user co-operative, bringing control to assistance users through economic independence. STIL has made an important contribution to the paradigm shift of disabled people from patients to citizens, which makes the STIL model very applicable in co-operative development by people with disabilities.

I wondered whether there is a need for such co-operative development in the Capital Health Region. In going back over the chronology of HSAG actions I have had the opportunity to inventory the types of activities, underlying strategies, and subsequent results. All of the group's meetings and efforts at building alliances were with the goal of reversing the Ministry of Health's decision to further limit the population receiving subsidised home support.

A tremendous amount of work went into all of these initiatives, work that is unrecognised, unpaid, and critical to the future health, happiness, and freedom of people with disabilities.

What is most striking when looking back through all of these efforts is not the ingenuity, resourcefulness, or articulateness of the Home Support Action Group, but rather the fact that despite this concerted effort, which combined research, education, and action, *nothing has changed*. In fact, the situation has deteriorated further since HSAG's summer meeting with the Provincial Health Minister. Members of the Group are living under the stress of rumours of impending cuts to CSIL, one member having his hours summarily cut over the Easter long weekend, and members involved in other advocacy organisations having received a barrage of calls from friends, acquaintances,

and members of the disabled community reporting further cuts to meal support and house-keeping over the summer. For a summary of the home support crisis in British Columbia please refer to Appendix Four, The Home Support Crisis: the faltering heart of community care.

Cuts to subsidised home support are totally unacceptable for people living with disabilities. They seemingly contradict statements made by the BC Ministry of Health, which upheld the importance of home support, pledging the allocation of further and future funds to home support and honouring the principle of meaningful community participation in decisions that directly affect home support users (Farnworth, Personal Communication, April 13, 2000). In October 2000, the Premier of BC announced \$9.3 million in new funding for various continuing care programs. While this funding is encouraging, and could indicate that the NDP Government recognises its responsibility to respond to the Home Support crisis in BC, the decision was made without meaningful inclusion of home support users. This exclusion of consumers is important, especially if we consider that few (if any) policy makers live with disability themselves. There appears to be no accountability in this Region to the principles of Health Care outlined by the province, not to mention the principles outlined in the Canada Health Act.

The Capital Health Region operated under a 5 million dollar deficit in 1999, and in 2000 is predicting further cuts to home support (Marin-Link, Personal Communication, February 15, 2000). Clients already surviving on the bare minimum of hours are looking down the barrel of future cuts, designed to ensure that clients with the *highest care needs* and living at the *highest levels of risk* continue to receive service. One hardly needs to point out the implications of this philosophy on the lives of people with disabilities. It has been commonly discussed among the group that, if we were discussing heart transplants or kidney dialysis, one could hardly imagine policy makers bantering over the “bare minimum” which should be publicly funded. There is a perception that people truly require heart transplants, yet no such understanding of home support. People with disabilities, people recuperating from surgery, people

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living with chronic illness, seniors living in their homes all require home support to facilitate their activities of daily living. Yet these services, according to provincial Health Ministry policy, are understood to be the least required and therefore least necessary of limited provincial funds allocated to the region. The result of this fiscal prioritising is the cutting of the right to community living and basic citizenship rights of people who require home support to live independently.

Thus, far from seeing their efforts bring about positive change in the region, the Home Support Action Group is facing a critical situation: the impending cuts to home support, and the fact that all avenues of action already attempted have had no effect have prompted two group members to look at the co-operative model as a way of attaining home support that is flexible and suited to the needs of consumers.

### **5.3 Next Steps: Further Research and the Personal Assistance Co-operative Society**

Meaningful involvement of consumers of home care/home support in decision-making is an important principle that has been too often ignored in policy development and in the delivery of publicly-funded home support services. Consumers have unique expertise that is relevant to decisions being considered by policy makers. Users can offer fresh, front line perspectives and balance to the funding/service provision debate. Unfortunately with restructuring of health care services provincially and regionally, consumers have not seen any fundamental shift in how community care services are delivered. The focus has remained instead on accommodating budget cuts and ensuring the success of various programs from the providers' points of view. In the Capital Health Region, methods of service delivery that are user-owned, directed, and centered are particularly lacking. For example, after the province of British Columbia reallocated responsibility for administration of health care to regions, enhanced home support services in the form of the

Community Transition Care Program were cut from the publicly-funded system. Subsidised home support has been capped in this region at 120 hours/month since October of 1999.

Because of this situation, and in light of my research findings, I present features of a home care/ home support co-operative which could meet the needs of those people who have been unable to access subsidised home support or have had their hours cut since 1994.

Two members of the Home Support Action Group, Gordon Argyle and Steve Reid, have sustained funding to develop a pilot home support co-operative in the Capital Health Region. In their words, the co-operative is being developed to fill the following gaps for people who use home support services:

When we went in search of options, we first considered the pros and cons of the current home support choices. We saw that clients of agency provided supports had the advantage of having little administrative involvement in their own care coordination or staffing matters. Their disadvantages were very little control over their home support hours and little choice over who provided the support. On the other hand, direct funded or CSIL home support clients have full and almost overwhelming responsibility for all aspects of getting their needs met, from hiring and training staff to administering and reporting on their budget to scheduling hours of support. The degree of personal involvement required for direct funded CSIL clients is similar to entrepreneurs running a business. Like entrepreneurs, the CSIL client's administrative challenges are rewarded with control and choice over the who, the how, and the when of their support services. The co-op model we propose would, once operational, present clients with another delivery option for their home support. We see the co-op as taking the strengths of the current options and building on them. Client choice and control with limited administrative responsibility. We also feel it is also important to build into the model elements of assistance

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beyond traditional “at-home” support - the things that enable people to carry on life while attaining education, building careers, running businesses, and generally participating in society. We see the proposed model as eventually providing additional services in supplement to just “at-home” support, so we have chosen the term “personal assistance” co-operative. (Argyle & Reid, personal communication, 23 October, 2000)

What follows is a summary of the goals for the Personal Assistance Co-operative Society (PACS), as well as a proposal for future collaboration between BCICS and PACS.

### **a) Summary of the goals for the Personal Assistance Co-operative Society**

The founders of the Personal Assistance Cooperative Society decided on these overall objectives:

1. The need for continuity of care reducing the stress of unskilled workers doing intrusive procedures and the immense amount of unpaid time the client spends training new workers, over and over.
2. The ability to control quality of care by delivering a training component that uses the ‘buddy system’ currently cut to two hours by the Health Region. Such a system has the new employee working alongside the experienced worker for several days as repetition of tasks -the best way to learn- and compatibility are established.
3. The ability to increase the flexibility of the tasks now being cut by the Health Region, which will permit the client to access the community, whether it be paid or unpaid work, community service, education, recreation, etc.
4. In return the co-operative will offer, by contract, the hours and shifts that

best fit a workers needs and guarantee a minimum number of hours should a client be hospitalised or on holiday. These security provisions are not available for the worker or client under the current system (Reid & Argyle, personal communication, July 12, 2000).

In achieving these over-arching goals, it became apparent to Reid and Argyle that their vision does not include just 'support in the home,' but both personal care and assistance in accessing the community. Therefore, they decided that the name of the endeavor would be "The Personal Assistance Co-operative Society." In keeping with the Provincial, Federal, and Regional Health Board guidelines and policy for providing recipients of home support equal access to all community life and an opportunity to offer their talents to the community, the founders believe that as this project develops, the co-operative method will offer a solution for many problems in health care service and delivery.

### **b) Proposal for future co-operation**

In *The Social and Economic Importance of the Co-operative Sector in Saskatchewan* (1998), Lou Hammond Ketilson identifies the co-operative sector as a viable arena in which to develop strategic partnerships among government, business, and community organisations. According to Ketilson, health co-operatives can present an important site of local innovation, with opportunities for key partnerships and for multi-sectoral collaboration.

An excellent opportunity for such collaboration has presented itself in the Capital Health Region with a pilot project in its infant stages, the Personal Assistance Co-operative Society. 'The disabled' have been regarded by health administrators not as people with different abilities and consequently different needs, but as non-people with non-abilities; not as people who can construct a life out of our different abilities, but as helpless individuals who have to be forced into a life that is constructed for them (Brisenden, 1986). A result of the current system is a state of conditioned uselessness, leading many people with disabilities and seniors to think they are a drain on society's resources, or imagine themselves as objects of charity who must be grateful for what they

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receive. The medical model of disability upon which service delivery is based now ignores the possibility that people with disabilities might be active people with something to contribute to society. This lack of control is especially important when considering the impact of personal assistance services on the consumer's quality of life.

Given that people with disabilities are unique individuals with individual physical and emotional needs, personal resources, and life circumstances, all of which will vary over time, consumers need to have alternatives to agency-centered personal care. The founders of the Personal Assistance Co-operative Society believe that consumer control is important in delivery of personal assistance services. Personal assistance services consist of practical help with all the tasks, which consumers cannot perform by themselves due to their current state of health. The concept 'home care', with the institutional connotations and the images of passivity and dependence suggested by the language, is incompatible with the goals of full participation and equal opportunities for people with disabilities and seniors in this community. People with disabilities active in this field have identified consumer control as the best guarantee for responsive systems. Choice is perceived as the key to independent living, and therefore inclusion, full citizenship, and self-determination.

Collaboration between BCICS and the Personal Assistance Cooperative Society would be in accordance with the four suggested preconditions for a partnership to meaningfully involve people with disabilities outlined by Krogh (1998) in *A Conceptual Framework of Community Partnerships: Perspectives of People with Disabilities on Power, Beliefs and Values*. Partners must:

1. make a commitment to collaborate;
2. understand the impact of commonly held beliefs and practices on limiting the participation of people with disabilities;
3. make power imbalances explicit; and
4. accept that the responsibility to work to redistribute the balance of power

more equitably within and among stakeholder groups necessitates personal, social and institutional change.

Collaboration would also be modeled after the key characteristics of a well-functioning community-driven approach, which are outlined in Appendix Four.

Some possible contributions that BCICS could make include the following: a documentation of the process of establishment of the Personal Assistance Co-operative Society; provision of information via the BCICS website and home care/home support research project on a variety of different models of co-operative home support service delivery; and assisting in the circulation of information before, during, and after the successful establishment of the co-operative. On the part of the Personal Assistance Co-operative Society, the partnership would entail a willingness to collaborate with BCICS researchers and to share information regarding the experience of the development of the co-operative, as well as a willingness to participate in the editing and publishing of any documents resulting from the partnership.

### **c) Concluding Remarks**

If we look back over the case studies presented here, we can surmise several things. The first is the importance of articulation of beliefs by co-operative developers, *and* the need for people in government to hear what they are saying. In CHCA, the founders were unwavering in their belief in the value of growing people; in STIL, founders adhered in all respects to the principles of the Independent Living movement. The second point is the principle of empowerment through co-operative development. Co-operatives were chosen in both cases as a means by which marginalised people could gain control over an aspect of their lives. The third point is the sense of power achieved by being able to define success from the point of view of the co-operative's members. One of the methods used by CHCA developers to discover the key characteristics of and criteria for job satisfaction was to define this 'quality' from the perspective of the workers and consumers. In

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STIL, quality of life is the driving force, and users of personal assistance were quick to distinguish between quantity and quality in service delivery. CHCA and STIL both show co-operative development to be well-suited to home health care. Hopefully their examples will prove useful in developing the Personal Assistance Co-operative Society in Victoria, and thereby bringing more liberating and gratifying forms of health care service to Canada.

## 6.1 Appendix One

### CHCA Development Milestones

#### 1982

- The Centre for Community Economic Development (CED), a unit within the Community Service Society of New York, forms.
- CED focuses on creating innovative programs designed to address the causes of poverty by empowering residents of low-income communities.
- Rick Surpin is hired to provide entrepreneurial leadership.

#### 1983-4

- Tom Bettridge and Peggy Powell are added to create a loan fund to support low-income enterprise and housing activities, and contribute to learning experiences and strategic thinking, respectively.
- The Industrial Cooperative Association of Boston, Mass. joins the team as consultants in structuring democratic firms.

#### 1985

- CHCA first starts operations.
- Wages and working conditions in the home care industry in New York are very poor: average private starting wage in NY City: \$3.75/hour, most workers receive the minimum wage of \$3.35/hour with no guarantee of additional raises.
- Benefits are non-existent; health insurance is virtually unknown in the industry.

#### 1986

- CHCA developers acquire a contract with Visiting Nurse Service of New York, providing close to 50% full-time employment (better than the industry average) and expanding CHCA's work force to nearly 100 paraprofessional aides.

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- Peggy Powell develops CHCA's entry-level training program in conjunction with a local community college.
- The CSS team appoints two employees to the board of directors to begin slow transition to worker control of the board.
- The management team initiates a campaign to urge employees to become worker owners.
- CHCA is still losing money; at this time most employees do not perceive the company to be worth owning.
- August: CHCA receives breakeven before principle payments, but quality of care is suffering due to rapid growth.
- Meg Chalmers is hired as a consultant to groom an African-American woman from within the company for the CEO position.
- This initiative does not work out; after two years CHCA is still without CEO adequate management structure.

### 1987

- Rick Surpin steps in as CEO.
- Peggy Powell and Kathy Perez begin to develop a new, totally internal, on-site entry-level training program.
- CHCA obtains more contracts to meet the goal of 70% full-time work; better benefit package are offered to the work force including life insurance and five paid personal days.
- March: over 40 workers choose to apply for membership in the cooperative; CHCA hold it's first election and five worker-members are elected to the board making it majority worker controlled.

### 1988

- CHCA approaches contractors for parity in contract pricing, resulting in wage rates around \$5.40/hour.
- New York state and local agencies begin to face severe revenue shortages.
- CHCA leads the formation of a New York City Home Care Work

Group, a city-wide coalition consisting of elder and disabled consumer organisations, public policy advocates, unions, provider agencies, and academic researchers, committed to viewing the home care system from the point of service delivery (the home).

- The Work Group urges the state to increase wage and benefit reimbursements for the entire home care system.
- New York State agrees to a new system of reimbursements.

### 1989

- Wage rates rise to \$5.70, with additional rates for difficult cases and seniority.
- CHCA establishes a limited health insurance policy for all employees.
- 50% worker ownership goal is met.
- Nursing Education Assistance Program forms to begin establishing a job ladder for home health aides.

### 1990

- Sherman Kreiner is hired to design and lead a major strategic planning process, looking especially at the question of growth.
- CHCA has 200 employees, in total.

### 1991

- 141 members out of a total of 250 employees have chosen worker ownership.

### 1992

- Annual growth rate is about 15%.
- 125 participants per year are in the entry-level training program, with an 80% completion rate.
- Three-tiered wage system based on seniority.
- 11% employee turnover rate.
- 70% of the total workforce are owners.

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- Start up of the Senior Home Care Aide Pilot Project, the Guaranteed Hours Pilot Project, and the Team Leader Training Program.
- Replication team is developed in accordance with strategic plan.

Adapted from: Brecher & Glasser, 1998; Dawson & Kreiner, 1993.

6.2 Appendix Two

CHCA Wages and Benefits, January 2000

Hourly Wages	
Starting Wage	\$6.25
1 Year	\$6.50 after 1,820 hours
2 Years	\$6.50
3 Years	\$7.00 after 9,100 hours
5 Years	\$7.25 after 14,560 hours
8 Years	\$7.50 after 14,560 hours
Vacation and Sick Times Policies	-Accrual starts at hire date -All accrual paid out
Vacation Accrual Rate and Maximum	Less than 2 years experience: 27 hours per 1,400 worked(1 hour per 52 hours worked)Maximum of 35 hours More than 2 years experience: 54 hours per 1,400 hours worked(1 hour per 26 hours worked)Maximum of 70 hours per year
Sick Time Accrual Rate and Maximum	64 hours per 1,400 hours worked(1 hour per 22 hours worked)Maximum of 84 hours per year
Jury Duty	\$45 per day for 3 days
Holidays	9 HolidaysTime-and-a-half for holiday hours if total weekly hours are under 40; double time if total weekly hours are over 40
Overtime	Time-and-a-half times base rate
Work Requirement for Benefits	Every other weekend No strict holiday requirementFull time availability
Health Insurance	Single coverage with access to Child Health Plus enrollment in the office

Adapted From:

Surpin, Rick. personal communication, September 13, 2000

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### 6.3 Appendix Three STIL Developmental Milestones

#### 1983

- Seminar organised by Dr. Adolf Ratzka on Independent Living.
- The Stockholm Independent Living Group forms.

#### 1984

- STIL receives a state grant, which covers the costs of formulating the STIL model and administration.
- Funding for STIL's first six personal assistants comes from six participating local governments within Stockholm County.
- 22 personal assistant users of a wide range of ages and disabilities participate in the pilot project.

#### 1987

- January: the STIL pilot project starts.

#### 1989

- STIL is founded and incorporated permanently.

#### 1993

- May 27: the Act concerning Support and Service for Persons with Certain Functional Impairments is passed.

#### 1994

- The Swedish Government's Personal Assistance Reform of 1994 is passed, modeled after STIL.

Adapted from: Ratzka, 1993; STIL homepage, Available Internet: <http://www.stil.se/>

## 6.4 Appendix Four

### **The Home Support Crisis: the faltering heart of continuing care**

- As a result of steady service cutbacks since 1994, tens of thousands of British Columbians are denied the hours and levels of home support service they require.
- Thousands of British Columbians who once qualified for home support now get nothing at all.
- Between 1994 and 1999, the number of British Columbians who receive home support decreased by about 20%, while the number of seniors increased by 13%.
- For most people who still receive publicly-funded home support, hours and service levels are drastically reduced.
- Housekeeping services have been virtually wiped out, forcing thousands of seniors and people with disabilities to live in unhealthy, unhygienic homes.
- Some regions of the province are particularly hard hit. In Quesnel, for example, between 1994 and 1999 there was a 25.3% reduction in the total number of home support hours provided, while the population of people 65 and older grew by 18.2%.
- The cutbacks are getting worse. Health regions are imposing stricter criteria and eliminating programs and services. Right now, across the province, home support recipients are being 'reassessed' and having their hours reduced or eliminated.

From: The Home Support Crisis: A Community Action Brief prepared by the BC Coalition of People with Disabilities

### 6.5 Appendix Five

#### **Key Characteristics of a Well-Functioning Community-Driven Approach**

##### 1. Community Participation

Community citizens', professionals', and organisations' direct participation is high in all phases of planning, implementation, and evaluation. The members of a community determine their own issues and goals. They then make a collective commitment to implement the solutions.

##### 2. Partnerships

The process involves partnerships, networking, and collaboration at all levels. Groups support each other's efforts to promote health and seek out ways to share resources in the pursuit of common goals.

##### 3. Shared power and decision-making

Community citizens, professionals, and organisations share power and decision-making. Decisions on programs, policies, and resources are made collectively instead of by one or two individuals in senior staff positions or "experts."

##### 4. Empowerment

The process fosters self-reliance and peer leadership. It builds on community members' strengths and facilitates self-empowerment, for example, the acquisition of relevant skills and experiences, which are re-invested in the community and contribute to its empowerment (attainment of the community citizens', professionals', and organisations' shared purposes based on their shared values). Relationships with professionals and institutions are negotiated. Professionals "do with" instead of "do for".

##### 5. Belief in the value of collective action

The community-driven approach lies on the paradigm of "building people through the accomplishment of tasks" rather than on the paradigm of "accomplishing tasks through people". Instead of only getting things done, you get them done with far greater creativity,

synergy, and effectiveness – and in the process you build the capacity to do more in the future as well. The spirit of this approach lies on the following principles:

- i) that people are capable of both perceiving and judging the condition of their health environments;
- ii) that they have the capacity to plan together in accordance with these judgements to change the conditions for the better;
- iii) that they can act together in accordance with these plans.

### 6. Community Analysis

Citizens, professionals, and organisations are directly involved in gathering, sharing, and analysing information about their values, needs and resources. This information forms the basis for their shared decisions about programs, services, policies, and resources. This analysis is not done “on” the community but “with” the community (Jefferies, personal communication, 2000).

Adapted From: *Key Characteristics of a Well-Functioning Community-Driven Approach*. (n.d.)

## BCICS Occasional Papers 4

### 7.0 Reference List

Adams, F., Gordon, F., & Shirey, R. (1993) . Innovative practices: Worker ownership in a low-paying and decentralized industry. *At Work*, March/April.

American Psychological Association. (1994) . *Publication manual of the American Psychological Association* (4th ed.) . Washington, DC: Author.

Barnes, C. (1998) . The social model of disability: A sociological phenomenon ignored by sociologists? In T. Shakespeare (Ed.) , *The disability reader: Social science perspectives* (pp. 65-78). London: Cassell.

Brecher, J., & Glasser, R. (1998) . “*We are the roots*” *An analysis of Cooperative Home Care Associates’ organizational culture*. Bronx, NY: Paraprofessional Healthcare Institute.

Brisenden, S. (1998) . Independent living and the medical model of disability. In T. Shakespeare (Ed.) , *The disability reader: Social science perspectives* (pp. 20-27). London: Cassell.

Chappell, N. L., & Prince, M. J. (1994) . *Social support among today’s seniors*. Victoria, BC: University of Victoria Centre on Aging.

Cocksedge, W. (2001) . *The role of co-operatives in the NTFP industry: Exploring issues and options using the case study of Salal (Gaultheria shallon: Ericaceae)* (BCICS Occasional Paper No. 2) . Victoria, BC: The BC Institute for Co-operative Studies, University of Victoria.

Co-operatives Secretariat (1998) . *The co-operative alternative to public service delivery*. Available Internet: <http://www.agr.ca/policy/coop/coop002.pdf>

Dawson, S. L., & Kreiner, S. L. (1993). *Cooperative Home Care Associates: History and lessons*. Bronx, NY: Home Care Associates Training Institute.

DiMarcello, C. (1996). ICA: Building community jobs by replicating model worker co-ops. *GEO Newsletter*. Ecological Democracy Institute of North America.

Frankenberg, R. (1997). Introduction: Racial subjects. In R. Frankenberg (Ed.), *Displacing whiteness: Essays in social and cultural criticism*. Durham, NC: Duke University Press.

Hollander, M. (1999). *The cost effectiveness of community based long-term care services for the elderly compared to residential care: A British Columbia perspective*. Unpublished doctoral dissertation. Faculty of Human and Social Development, University of Victoria, British Columbia.

International Co-operative Alliance. (1995). *Statement on the co-operative identity*. Available Internet: <http://www.coop.org/ica/info/enprinciples.html>

Ketilson, L. H. (1998). *The social and economic importance of the co-operative sector in Saskatchewan*. Saskatoon, SK: Centre for the Study of Co-operatives, University of Saskatchewan, & Saskatchewan Department of Economic and Co-operative Development.

Kirby, S. L., & McKenna, K. (1989). *Experience, research, social change: Methods from the margins*. Toronto, ON: Garamond Press.

Krogh, K. S. (2000). *Beyond four walls. Disability, work and home support policy: Linking research to multi-sector action*. Unpublished research report.

## BCICS Occasional Papers 4

Krogh, K. S. (1998) . A conceptual framework of community partnerships: Perspectives of people With disabilities on power, beliefs and values. *Canadian Journal of Rehabilitation*, 12, 123-134.

Krogh, K. S. (1996) . Ethical issues in collaborative disability research: Applications of the partnership agreement framework. *International Journal of Practical Approaches to Disability*, 20, 29-35.

Ratzka, A. (2000) . Stockholm Cooperative for Independent Living (STIL) homepage. Available Internet (Accessed September 18, 2000): <http://www.stil.se/>

STIL can be contacted at Bondegatan 39 – 116 33 Stockholm. Tel, fax or text tel: 08-50622150/70/75.

Ratzka, A. (1998) . *Personal assistance network questionnaire*. Available Internet: <http://www.independentliving.org/PANetwork/questionnaire.html#anchorex>

Ratzka, A. (1996) . STIL, the Stockholm Cooperative for Independent Living. Available Internet (Accessed June 22, 2000): <http://www.independentliving.org/STIL/STILlongdescription.html>

Ratzka, A. (1993) . The user cooperative model in personal assistance: The example of STIL, the Stockholm Cooperative for Independent Living. In B. Duncan, & S. Brown (Eds.) , *Personal assistance services in Europe and North America: Report of an international symposium*. New York, NY: Rehabilitation International and World Institute on Disability.

Ratzka, A. (1986) . *Independent living and attendant care in Sweden: A consumer perspective*. New York, NY: World Rehabilitation Fund.

Surpin, R. (2000) . *Affiliation agreement between Cooperative Home Care Associates and Independence Care System*. Bronx, NY: Cooperative Home Care Associates.

Surpin, R., & Dawson, S. L. (2000) . *Case statement: Independence care system, a managed long-term care demonstration program for people with disabilities*. New York, NY: Independence Care System.

Wilner, M. A., & Wyatt, A. (1998) . *Paraprofessionals on the front lines: Improving their jobs – improving the quality of long-term care*. Washington, DC: Paraprofessional Healthcare Institute.

Wolfensberger, W. (1975) . *The origin and nature of our institutional models*. Syracuse, NY: Human Policy Press.

Zimmer, Z., & Chappell, N. (1993) . *Neglected needs and emerging opportunities in seniors' markets: An argument for further research*. Victoria, BC: University of Victoria Centre on Aging.

## **BCICS Occasional Papers 4**

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<http://www.stil.se/>

University of Wisconsin Centre for Co-operatives

<http://www.wisc.edu/uwcc/info/aushlth.html>

## BCICS Occasional Papers 4

### Personal Communications

Argyle, Gordon (2000, July 12; October 23)

Argyle, Gordon (1999, October 20)

Baker, Linda. (2000, June 12) *ARCH, The National Resource Centre for Respite and Crisis Care Services*. <http://www.ichtop.com/archbroc.htm>

Blight, Claudia (2000, July 12)

Brown, Tim (2000, June 5) National Association for Home Care

Ditto, Bill (2000, May 19)

Farnworth, Michael (2000, April 13)

George, Claudia (2000, June 15)

Hendricks, Mary (2000, May 1)

Janick, Steve (2000, June 12) New Jersey Personal Assistant Services Cooperative, Inc.

Kimpson, Sally (2000, May 4; February 15)

Kimpson, Sally (1995, March 3)

Landry, Terry, & Ashmore, Keith (1999, December 20)

Litvak, Simi (2000, May 18) World Institute on Disability <http://www.wid.org>

MacDonald, Rod (1995, March 31)

McNeil, Margaret (2000, April 20; January 21)

McWhorter, Alan (2000, May 29) Kingston and District Association for Community Living Worker Co-ops.

Moseley, Charles (2000, May 23) Institute on Disability, University of New Hampshire

## BCICS Occasional Papers 4

Ohya, Masao (1999, October 25)

Ratzka, Adolf (2000, September 13; June 26)

Reid, Steve (2000, April 29; May 3; July 12; October 23)

Rock, Hon. Allan (2000, May 4)

Surpin, Rick (2000, July 24; September 13)

Wood, Kevin (2000, June 16) *Long Term Care Campaign*

## BCICS Occasional Papers 4

### Related Works

Anderson, M., & Parent K., Nishihama, S. & Mueller, B. (1999) . *Putting a face on home care: CARP's report on home care in Canada 1999*. Kingston, ON: Queen's Health Policy Research Unit.

Argyle, G., & Kimpson, S. (1999, December 3) . Home support – not your problem? *Times Colonist*.

Aronson, J., & Neysmith, S. M. (1996) . “You’re not just in there to do the work:” Depersonalizing policies and the exploitation of home care workers’ labor. *Order and Society*, 10, 59-77.

Bollier, D., & Rowlands, P. (1992) . Rick Surpin (A). In K. O. Hanson (Ed.) , *The business enterprise trust* (pp. 1-13) .

Boyer, R. (1994) . *A community health centre for Saint John: Linking our community to health, community needs study, a snapshot of health and the Saint John community*, Draft. Saint John: The Steering Committee, Community Health Centre.

Brecher, J., & Glasser, R. (1999) . *Valley Care Cooperative: A retrospective*, Draft. Boston, MA: Cooperative Charitable Trust.

British Columbia Coalition of People with Disabilities. (1999) . *Brief to the Continuing Care Review Committee*. Vancouver, BC: Author.

Barkley, M., & Canadian Co-operative Association — British Columbia Region. (1995) . *Handbook for developing a cooperative community health centre*. Brentwood Bay, BC: BC Canadian Co-operative Assoc – BC Region.

*Business Plan.* (1999) . New Jersey Personal Assistant Services Co-operative, Inc. Long Branch, NJ: NJ PAS Co-Op Inc.

Campbell, M., Copeland, B., & Project Inter-Seed Research Team. (1999) . *Project Inter-Seed: Learning from the health care experiences of people with disabilities.* Victoria, BC: University of Victoria.

Campling, J. (Ed.) . (1981) . *Images of ourselves: Women with disabilities talking.* London: Routledge & Kegan Paul.

Capital Health Region. (2000, January 5) . *Capital Health Region adjusts access to subsidized home support services.* Victoria, BC: Author.

Capital Health Region. (1999, December 20) . *Criteria for scoring risk factors for new referrals for Long Term Care Program services,* Draft. Victoria, BC: Author

Chappell, N. L. (1992) . *Social support and aging.* Vancouver, BC: Butterworth.

Chappell, N. L., & Litkenhaus, R. (1995) . *Informal caregivers to adults in British Columbia.* Victoria, BC: Centre on Aging, University of Victoria, & The Caregivers Association of British Columbia.

Community Development Co-operative of Nova Scotia Limited. (1995) . *Feasibility study proposal on the possible use and application of the co-operative model in home care.* Halifax, Nova Scotia: Author.

Danard, S. (2000, April 30) . Founder's daughter pleads for Canada to rescue system. *Times Colonist*, pp. A1-A2.

Dawson, S. L., Powell, P., & Surpin, R. (2000) . *Closure: Cooperative Home Care of Boston, accomplishments and analysis.* Bronx,

## BCICS Occasional Papers 4

NY: Paraprofessional Healthcare Institute.

Doe, T., & Kimpson, S. (1999) . *Enabling income: CPP disability benefits and women with disabilities*. Ottawa, ON: Research Directorate, Status of Women Canada.

Fawcett, G. (2000) . *Bringing down the barriers: The labour market and women with disabilities in Ontario*. Ottawa, ON: Canadian Council on Social Development.

Fawcett, G. (1996) . *Living with disability in Canada: An economic portrait*. Ottawa, ON: HRDC (Office for Disability Issues).

George, C. (1999) . *Senior Home Care Cooperative*. Available Internet (Accessed June 6, 2000): <http://care.spaces.org/>

*Health Care Cooperatives start-up guide*. Available Internet (Accessed May 25, 2000): <http://www.agr.ca/policy/coop/health/index-e.html>

Jaruzel, M. I. (1999) . New system will aid severely disabled. *@mott.now*, 2, 8-9.

Jaruzel, M. I. (1999) . 'Quicker and sicker' policy changes affect home health care. *@mott.now*, 2, 6-7.

Kimpson, S., & Reid, S. (2000, March 1) . *The importance of subsidized home support to people with disabilities*. Presentation to the Capital Health Region Board of Directors.

Krogh, K. S., & Lindsay, P. H. (1999) . Including people with disabilities in research: Implications for the field of augmentative and alternative communication. *AAC Augmentative and Alternative Communication*, 15, 222-233.

*Long Term Care Campaign.* Kevin Wood (Contact). PO Box 27394, Washington DC, 20038. Phone: (202)434-3744.

Meekosha, H. (1998) . Body battles: Bodies, gender and disability. In T. Shakespeare (Ed.) , *The disability reader: Social science perspectives.* London: Cassell.

Morris, M., Robinson, J., & Simpson, J. (1999) . *The changing nature of homecare and its impact on women's vulnerability to poverty.* Ottawa, ON: Status of Women Canada.

*New Jersey Personal Assistant Services Cooperative, Inc.* Steve Janick, (Contact) P.O. Box 3175, Long Branch, New Jersey. 07740-3175, USA. Voice (732)870-6600, Fax (732)870-6669, TDD (732)870-8886

Pistell, D. (2000, April 30) . More than housework. *Times Colonist.*

Reitsma-Street, M., Hopper, A., Seright, J., & Capital Urban Poverty Project. (2000) . *Poverty and inequality in the Capital Region of British Columbia: A report of the Capital Urban Poverty Project.* Victoria, BC: University of Victoria Faculty of Human and Social Development.

Rioux, M. H. (1993) . Foreword. In S. Torjman (Ed.) , *Nothing personal: The need for personal supports in Canada.* North York, ON: Roeher Institute (York University).

Senior Home Care Alternative. (1999, April 15) . *Minutes of annual board meeting.* Chicago, IL: Author.

Senior Home Care Alternative. (1999) . *Report of first quarter ending March 31, second quarter ending June 30, third quarter ending September 30.* Chicago, IL: Author.

## BCICS Occasional Papers 4

Senior Home Care Alternative. (1998) . *Report of first quarter ending March 31, second quarter ending June 30, third quarter ending September 30, fourth quarter ending December 31*. Chicago, IL: Author.

Senior Home Care Alternative. (1998, October 8) . *Board meeting minutes*. Chicago IL: Author.

Senior Home Care Alternative. (1998) . *Proposals submitted*. Chicago, IL: Author.

Senior Home Care Alternative. (1997, April 24; July 24; October 22) . *Board meeting minutes*. Chicago, IL: Author.

Senior Home Care Alternative. (1997, October 22) . *Quarterly report*. Chicago, IL: Author.

Senior Home Care Alternative. (1997) . *Phase II/Objectives and activities*. Chicago, IL: Author.

Senior Home Care Alternative. (1997) *Proposals submitted, January – July 1997*. Chicago, IL: Author.

Senior Home Care Alternative. (1996, October 24) . *Quarterly report*. Chicago, IL: Author.

*Senior Home Care Cooperative*. Mary Signatur, & Claudia George (Executive Directors). 3819 N. Ravenswood, Chicago IL 60613. Available Internet: <http://www.care.spaces.org/about.htm>

Spack, T. (1998) . Review of the Canada Health Act: What are the rights and entitlements of Canadians in terms of health care? In *Workers' Centre*, Communist Party of Canada (Marxist-Leninist), Hardial Bains Resource Centre, 2 April.

Spear, R., Leonetti, A., & Thomas, A. (1994). *Third sector care: Prospects for co-operatives and other small care providers*. Milton Keynes: The Co-operatives Research Unit, Open University.

Watson, N. (1998). Enabling identity: Disability, self and citizenship. In T. Shakespeare (Ed.), *The disability reader: Social science perspectives* (pp. 147-162). London: Cassell.

Watts, R. (2000, April 18). Cutbacks threaten home nursing. *Times Colonist*, pp. C1, C3.

Your guide to cooperative business development: Creating Opportunities, Optimizing Possibilities. *Coop Business Solutions*. (2000). Philippines: Visayas Cooperative Development Centre and Canadian Co-operative Association.

## BCICS Occasional Papers 4

### Notes

<sup>1</sup>According to the Publication Manual of the American Psychological Association, 4<sup>th</sup> ed., “the guiding principle for ‘nonhandicapping’ language is to maintain the integrity of individuals as human beings” (APA, 1994, p. 53). I prefer to use “person with a disability” or “people with disabilities” as descriptive terms as these are used by my friends and co-workers. As a general rule, “person with \_\_\_\_\_,” “person living with \_\_\_\_\_,” and “person who has \_\_\_\_\_” are neutral and preferred forms of description (APA, 1994, p. 53).

<sup>2</sup>Terms referring to age can be problematic. For example, the term ‘elderly’ can be considered pejorative as an adjective. The Publication Manual of the American Psychological Association, 4<sup>th</sup> Ed. indicates a preference for the term ‘older person’ (APA, 1994, p. 53). I use the term ‘senior’ to refer to a transitional stage of life in which people may find themselves with decreasing capabilities for independent living, as opposed to a specific age bracket (such as over 65).

<sup>3</sup>The term ‘consumers’ refers to people using home health care services and/or support for independent living. Krogh (1996) defined consumers as “citizens who have expertise based on their experience of living with a disability” (p. 29).

<sup>4</sup>I use the term ‘marginalised’ to describe a state of relative disempowerment as compared to the ‘mainstream’ (ie. the status quo, the norm). Marginalised people often experience feelings of insignificance, of existing on the edge of where the forces of power and influence are in society. “People find themselves on the margins not only in terms of resources. Knowledge production is also organised so that the views of a small group of people are presented as objective, as ‘the Truth.’ The majority of people are excluded from participating either as producers or participants in the creation of knowledge” (Kirby & McKenna, 1989, p. 7).

<sup>5</sup>I use the word ‘deconstruct’ to indicate that I intend to define and discuss the multiple meanings of these concepts.

<sup>6</sup> I use the expression ‘temporarily able-bodied’ to suggest that disability and ability are not finite categories – we will, in all likelihood, eventually become disabled.

<sup>7</sup> The term ‘model’ will be used in this project to refer to a consistent pattern in which the behaviour of persons is structured by other persons who exercise(d) authority over them (Wolfensberger, 1975).

<sup>8</sup> It is interesting to note the contradiction that, while the World Health Organization definition of health is holistic (health is seen as a resource for daily life, not the objective of living), the classifications of impairments, disabilities and handicaps are rooted in the western medical tradition and focus on limitations of the *disabled*.

<sup>9</sup> Participatory action research combines research, education and action (Hall, as cited in Krogh, 2000).

<sup>10</sup> There are other systemic factors in our society which prohibit people with disabilities from working (eg. the structure of Disability benefits, attitudinal barriers, inaccessible workplaces). For additional reading on this subject, see Doe and Kimpson (1999).