# (RE)QUESTING COMMUNITY:

## A CRITICAL ANALYSIS OF COMMUNITY IN THE DISCOURSE OF

## DISABILITY RIGHTS AND COMMUNITY BASED REHABILITATION

By

## CATHERINE L. LYSACK

A Thesis

Submitted to the School of Graduate Studies
In Partial Fulfilment of the Requirements for the Degree

## DOCTOR OF PHILOSOPHY

Department of Community Health Sciences
University of Manitoba
Winnipeg, Manitoba

© July 1997

*Your file   Votre référence*

*Our file   Notre référence*

0-612-23631-5

Canada

THE UNIVERSITY OF MANITOBA

FACULTY OF GRADUATE STUDIES
*****
COPYRIGHT PERMISSION PAGE

(RE)QUESTING COMMUNITY: A CRITICAL ANALYSIS OF COMMUNITY
IN THE DISCOURSE OF DISABILITY RIGHTS AND COMMUNITY BASED
REHABILITATION

by

CATHERINE L. LYSACK

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University

of Manitoba in partial fulfillment of the requirements of the degree

DOCTOR of PHILOSOPHY

CATHERINE L. LYSACK    1997 (c)

## ABSTRACT


The purpose of this research is to demonstrate the penetration of community language and the power of the idea of community in the international discourse of disability rights and community based rehabilitation. A critical postmodern approach provides the overall theoretical framework for this research. Interviews with 38 key-informants, archival review of program and policy materials as well as participant-observation in the field over a 24 month period provide the data for the comparative case study.

The research findings show that while both approaches to disability are committed to community based services and share a similar language of community, the *kind* of community to which they refer is not the same. For disability rights, based on the independent living philosophy, community implies identity and belonging. Community refers to a group of like-minded individuals focussed on the rights of people with disabilities. For community based rehabilitation however, community is geographical. Community refers to a physical locale. More importantly, and irrespective of the kind of community images generated, these two ideologies tend to attribute to the idea of community traditional features of community that may not accurately reflect the reality of present day communities, thus complicating our understanding of the fundamental processes of community participation and community organizing related to health.

This analysis has shown community to be a complex and persuasive concept of great strategic utility within the international discourse on disability and beyond.

## ACKNOWLEDGEMENTS

ii

# TABLE OF CONTENTS

## LIST OF FIGURES

## ABBREVIATIONS

| | |
|---|---|
| CBR | Community Based Rehabilitation |
| CCD | Council of Canadians with Disabilities |
| DPI | Disabled People's International |
| DPO | Disabled Peoples Organization |
| IL | Independent Living |
| ICACBR | International Centre for the Advancement of Community Based Rehabilitation |
| ILO | International Labour Organization |
| ILRC | Independent Living Resource Centre |
| NGO | Nongovernmental Organization |
| PHC | Primary Health Care |
| RI | Rehabilitation International |
| UN | United Nations |
| UNESCO | United Nations Educational Scientific and Cultural Organization |
| UNICEF | United Nations International Children's Emergency Fund |
| WID | World Institute on Disability |
| WHO | World Health Organization |
| YPAC | Yayasan Pembinaan Anak Cacat (Indonesian Society for the Care of Disabled Children) |

# GLOSSARY

**Disability . . .**

A restriction or lack of ability to perform an activity in a normal manner.
(WHO in Verbrugge & Jette, 1994, p. 2)

**Community Based Rehabilitation . . .**

A strategy within community development for the rehabilitation, equalization of opportunities and social integration of people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, educational and social services.
(ILO/UNESCO/WHO, 1994, p. 2)

**Independent Living . . .**

A process of consciousness raising and empowerment. This process enables disabled people of all ages and with all types of disabilities to achieve equalization of opportunities and full participation in all aspects of society. Disabled people must be in control of this process. Meaningful choices must be available in order to exercise control. (DPI, 1995, p. 1)

**Rehabilitation . . .**

A goal-oriented time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing him or her with the tools to change her or his own life. It can involve measures intended to compensate for the loss of function or a functional limitation (for example by technical aids) and other measures intended to facilitate social adjustment or readjustment.
(UN, 1983, p. 3)

# THE STUDY

*Science is different from many other human enterprises ... it is the passionate search to confirm or deny ideas, the vigour of its substantive debate, and in its willingness to abandon ideas that have been found wanting. If we were not aware of our own limitations ... if we were not seeking further data ... if we did not respect the evidence, we would have very little leverage in our quest for the truth. Through opportunism and timidity we might then be buffeted by every ideological breeze, with nothing of lasting value to hang on to.*

Carl Sagan, The Demon-Haunted World, 1995, p. 263.

## Introduction

There is something unsettling about our present time. There is a vague sense of unease, of disquiet and disillusionment. It seems that society is lacking overall coherence and that its institutions have failed. Despite intensive efforts to the contrary, society seems to be unravelling at the seams. In the North[1], an increasing disparity in wealth portends a long term economic decline for many and the prospect of rising class conflict (Ehrenreich, 1989; Ignatieff, 1994). Globally, the scientific and humanitarian advances of this century have not addressed the world's social, political, health and environmental problems, and arguably have exacerbated them (Alvares, 1992; Jacobs, 1992; Nandy, 1990). Hence, while enjoying the conveniences and pleasures of

---

[1] As a convention, and throughout this thesis, countries are designated Northern or Western rather than "developed," and Southern rather than "developing."

technology unknown to other ages, we feel dissatisfied, unfulfilled, rather lost and disconnected, even cynical. Why?

Kingwell (1996) suggests, in his provocative book *Dreams of the Millennium*, that our feelings of collective insecurity can be captured in the phrase millennium anxiety. Kingwell's assessment is that the impending passing of one millennium and the dawning of another creates favourable conditions for a new found sensitivity to popular ennui. However, the fact that we are entering the 21st century alone seems insufficient to explain the degree of existential anxiety gripping society. We are experiencing a kind of collective social fatigue, a phenomenon Charles Taylor (1991) calls the malaise of modernity.

This existential malaise is not unique to our time. Rollo May wrote in 1950 that we were living in "an age of anxiety" characterized by a "nameless and formless uneasiness." May argued then that the present anxiety stemmed from society's emphasis on the free and rational individual and his emancipation from guild, church and community. The problem as May saw it was how interpersonal community (psychological, economic, ethical) was to be reconciled with the values of individual self-realization, thus freeing members of society from a sense of isolation. May concluded that competitive individualism "militates against the experience of community, and that lack of community is a centrally important factor in contemporaneous anxiety" (p. 169).

May's depiction of collective anxiety in the 1950s is an echo of earlier expressions of a more distant anxiety caused by social transformations at the dawn of

2

the industrial age. More than a century ago, industrial development ignited fears about the ills of capitalism and how it would extinguish the positive features of rural social life. For those like Weber, Marx, Tönnies and others, the individual pursuit of capital spelled the end of traditional life where reciprocity and caring carried the day (Bell & Newby, 1971). These social observers protested the forced transition. And they mourned the loss of community.

Today, there are disquietingly similar rumblings. Like a full century earlier, economic conditions are once again driving these changes in social relations. In the 1990s however, it is the power and immediacy of information technologies rather than mechanization that lies at the heart of the transformation. We live in an information age where face-to-face communication is increasingly redundant. But isolation breeds anxiety. Are social conditions ripe once again for a (re)questing of community -- a yearning for a better life of the past?

The themes of civil unease, social dislocation, isolation, and anxiety about the future are recurring ones. So, we must ask whether the contemporary heights of collective fatigue and vulnerability represent an intensification of these themes, or whether there is something uniquely different about the present. While one must constantly guard against an embrace of the present as unique, there are indications that the contemporary situation is novel in several respects. Walzer (1994), for example, argues that contrary to earlier periods in history where interdependence was a more prized social value, the present day is overwhelmingly individualistic. Walzer states,

3

> Compared to the men and women of any earlier, old-world country, we are radically liberated, all of us. We are free to plot our own course, plan our own lives, choose a career, a partner (or succession of partners), a religion (or no religion), a politics (or an antipolitics), a life-style (any style) -- free to "do our own thing." (p. 187)

These levels of personal freedom and flexibility have not brought peace and contentment. Rather, they have added to feelings of listlessness and alienation. Eventually, these feelings can culminate in a deep sense of inadequacy and meaninglessness. Sardar (1992) states,

> We keep asking ... what is wrong with God? With democracy? With socialism? With art? With sex?: It seems as though we live with the feeling of an all-encompassing crisis without being able, however, to identify its causes clearly. (p. 498)

Walzer and Sardar are not alone. Denzin too (in Sardar, 1992) sees contemporary society as fundamentally different from the past and calls this new period of history postmodernity. Denzin further claims that unfettered individualism is only one of its many new, and mostly problematic, features. Calling it a break with the past, Denzin describes postmodernity as

> an erasure of the boundaries between the past and the present; an intense preoccupation with the real and its representation; a pornography of the visible; the commodification of sexuality and desire; a consumer culture which objectifies a set of masculine cultural ideals; intense emotional experiences shaped by anxiety, alienation, resentment, and a detachment from others. (p. 503)

Harvey (1995) adds that postmodernity is also a time lacking moral universals. Truth,

4

reason and authority are fundamentally questioned, and reality, ultimately, is reduced to interpretation and personal opinion. If we do live in postmodern times, as Denzin and Harvey suggest, then it is little wonder that people feel disconnected and alone.

If we are to assume for a moment that postmodernity legitimately describes our contemporary situation, deeply penetrated as it is with feelings of insecurity and isolation, can we also imagine a path to firmer ground? Is there a way to diminish our collective anxiety?

The concept of community may provide the answer, for community may represent a way out of the indeterminate present. Community conjures up images of a better past -- whether or not an ideal form of traditional community existed or not. So, while Tönnies' search for community was driven by the feelings of loss he tied to the industrial revolution, our contemporary longing for community may not be so dissimilar. In emotionally unstable and unsatisfying environments, people may seek out and cling to ideas, people, and things (including community) in the hope that it will reduce these anxieties. But are these retrospective imaginings anything more than sentimentalism? Did an ideal form of community exist in the historical past and can we come to know its qualities and the conditions required to recreate them? What is it about community exactly that renders it so attractive an idea in contemporary times?

Human beings, while attracted to the unknown and the allure of adventure, have also likely always sought the comfort and communion of others. In fact, some form of collective association may define and satisfy the most fundamental of human needs. For many, the word community triggers positive images of sharing and caring, of

5

warmth, belonging and understanding. Its mention engenders a sense of familiarity and stability as people recall special people, places and times. Community is also a reassuring word, emphasizing principles of acceptance, nurturance and reciprocity. The goodness of these recollections coupled with their familiarity permit feelings of constancy and predictability, even control to take root. Hence, community is an important psychological resource. Community provides solace. It is bedrock. Community satisfies our longing for security, by linking an unknowable future to the understood past. Community is the antidote to anxiety.

Anxiety in contemporary society has not diminished. Furthermore, we appear equally unsure whether returning to previously lost forms of traditional community or experimental efforts to create new forms of community are the means by which to secure a more desirable future. This predicament too produces anxiety. Harvey (1995) asks, "if no one 'knows their place' in this shifting collage world, then how can a secure social order be fashioned or sustained" (p. 302)? In order to understand our society then, at least in its broadest dimensions, and to establish some guideposts for the future relations within and between the social groups called communities, it is imperative to grasp the meaning of community -- its rhetoric and its reality. Research interested in the idea of community must engage this concept at a level well beyond the word as commonly used and understood.

To undertake a comprehensive theoretical investigation of the idea of community would entail an exploration of community in all of its myriad forms and dimensions in all parts of the world, as well as an explication of its historical

6

development and cultural dimensions. The goals and scope of this research are far more modest. The aim of this research is to explore the language and idea of community. This analysis is also situated within the context of one distinct social group, people with disabilities. More specifically, the analysis focuses on the disability rights movement based on the independent living (IL) philosophy and community based rehabilitation (CBR). Stated most simply, this research examines the impact of the idea of community on disability ideology.

To be clear, this research does not address many other related questions. It does not, for example, examine who belongs to the community called disabled people. Neither does it explore the reasons for seeking membership in this group, or suggest how such communities might be identified or strengthened. It does not address the question of whether or not people with disabilities constitute a disadvantaged or oppressed community. The research does not offer a new definition of community. And finally, this research does not aim to explore the existence of ideal forms of community in the historical past. The task of this research is much more narrowly defined. It seeks only to describe the power of the idea of community in the ideology of IL and CBR.

A critical analysis of community such as that proposed demands that three distinct aspects of community be distinguished: 1) community as an idea, a concept; 2) the rhetoric of community, community as a word in language; and 3) the essence or nature of "real" communities. This research is intent upon explication of the first two aspects of community. There will be occasions where an interweaving of all three

7

strands will be necessary, and even desirable. For the most part however, it is incumbent upon the researcher to hold these separate strands of community apart. Still, critical analysis requires of the researcher an unflinching regard for the power of language to infiltrate analysis. As this research aims to illustrate, the conceptual liquidity of community renders it a most powerful tool of semantic and social persuasion.

## Approaches to Community Study

Communities, as physical groupings of people, have existed from the beginning of humankind and social relations within these groupings were undoubtedly present. These two fundamental aspects of community, geographical locale and social interaction, give rise to community's conceptualization problems. George Hillery's pessimistic conclusion in 1955, after classifying 94 definitions of community, was that the only element common to all definitions was that they dealt with people. Hillery's lament also foreshadows the contemporary difficulties confronted in efforts to establish a clearer understanding of the meaning of community (Bell & Newby, 1971; Nisbet, 1967).

Community can be studied from a variety of viewpoints, dependent upon what meaning of community is taken. For example, the physical localities in which people live and work are commonly called communities. These localities are spatially organized and delineated. Community studies that focus on a town or a village, for example, exemplify this approach. Communities can also be understood as units of

8

social interaction that have little or nothing to do with geographical boundaries. These communities may be based on ethnic identity or shared purpose, for example. And of course, these two main kinds of community often overlap substantially. Thus, various kinds of communities exist and all can be the focus of study.

Communities are also organized in certain ways and these structures may be the focus of a study of community. Organizational hierarchies may be the research focus, so too could be the process of community formation or the ways in which power operates in communities. Another approach to the study of community is to focus on the relationship of the individual to the community, or the relationship between the community and larger society. For this thesis research however, our interest is in the *idea* of community. While seemingly ordinary and commonplace, community is a relatively complex and unexpectedly elusive concept. Studying the idea of community is nonetheless important because it represents an essential first step to understanding what is meant by those who assert community status. Critical analysis is also the only way to gain insight into the strategic use of this powerful concept.

## Purpose of the Research

The idea of community must be studied within a context. This study examines the idea of community within the international context of disability. The specific goal of this research is to critically analyze the idea of community, a concept embedded in the ideologies of two emerging trends in disability, the heightened visibility and viability of the disability rights movement based on the IL philosophy, and a significant

9

turn within professional rehabilitation toward greater attention to and adoption of community development strategies and CBR. The primary purpose in studying the idea of community is to reveal the plasticity of this word and demonstrate its persuasive power. Although very preliminary research in this area has been conducted (Lysack, 1996a; Lysack & Kaufert, 1994a & 1996), much work remains.

The purpose in bringing together these two trends in international disability is not to counterpose IL and CBR artificially as "duelling ideologies." Rather, the intention is to compare and contrast the ways in which the idea of community is understood in each. The overarching goal is to understand how the idea of community operates in these two models, and what kinds of communities are assumed and asserted by IL and CBR on this basis. Hence, the research concerns itself with the following:

1.      A demonstration of the ubiquity of community language in disability and rehabilitation in both Northern and Southern contexts;

2.      A critical review of the meaning of community and disability;

3.      An historical examination of two responses to disability internationally, the disability rights movement based on the IL[2] philosophy, and CBR;

4.      The differential construction and use of community by IL and CBR; and

---

2 Throughout this thesis, the terms independent living (IL), the disability rights movement, and the disabled consumers movement are used interchangeable to signify the organized efforts of people with disabilities themselves to improve their lives. While there is significant overlap between these initiatives, there are important distinctions between them as well. For convenience, and as a logical counterpart to the abbreviation CBR however, IL will be used to signify the efforts of all of these streams of the disability movement.

5.    A critical discussion of how the idea of community permeates and mediates the theoretical underpinnings and contemporary practice contexts of IL and CBR.

The main argument advanced in this research is that despite IL and CBR's significant use of community language and apparent commitment to something called community based services, these ideologies understand and assert community in two quite different ways:  For IL, the idea of community is inextricably linked to issues of personal identity and belonging;  for CBR, community is grounded in geographical place.  Both IL and CBR, however, tend also to attach to community traditional (perhaps even mythical) qualities.  Community envisioned in this traditional sense may bear little correspondence to the "living and breathing" entities called communities, however defined.  The idea of community is so malleable that it can be imagined in a myriad of different forms and manipulated to conform to a diversity of contexts and purposes.

## Rationale for the Disability Context

Why study community within the context of disabled people?  In what way are insights generated in the disability context relevant more broadly?

First, people with disabilities are representative of the general population in many significant ways.  While the specific label disabled is shared, disability refers to a wide variety of physical and mental conditions (Groch, 1994).  Intensifying this heterogeneity is that disability may be acquired at any point along the life cycle, through accident or by disease, both predictable and not.  Men and women, young and old, and those in every occupational category and income bracket can and do, at some

11

time or another, lose some faculty or function and thus become disabled. Thus, people with disabilities represent humanity as a whole.

Second, people with disabilities as a group have been, in North America at least, relatively effective in achieving their goals. In Canada they have achieved formal recognition in the Charter of Rights and Freedoms (1992) and the Canadian Human Rights Act. Through the mobilization efforts of disability rights activists in the United States, the Americans with Disabilities Act was signed into law in July 1990. At the international level too, the World Programme of Action Concerning Disabled Persons (1983) was a landmark document, entrenching the rights of the disabled in official United Nations (UN) policy. People with disabilities have asserted themselves as a group with important claims. And at least to some degree, society has responded. Closer examination of this group may reveal factors contributing to their apparent success.

Finally, if the old adage is true, that the goodness of society is measured by the treatment of its least privileged members, then perhaps a case can be made for an analysis of community within the context of disability. Then, the experiences of people deemed most different, and least able, in fact represent the richest source possible of revelatory insight into the human condition.

## Relevance of the Research

The importance of community as a guiding concept in the development of disability policy in Canada is evidenced by its prominence within the high-profile

12

document, the Obstacles Report, commissioned shortly after the declaration of the

International Year for Disabled Persons in 1980. The importance of community is

proclaimed in Recommendation 75 of the Obstacles Report which states

> that the federal government promote a more suitable and cost-effective
> alternative to institutionalization by introducing enabling legislation for cost-
> sharing with provinces and municipalities the provision of comprehensive
> services *to assist disabled persons to live and function independently in the
> community* [italics added]. (Parliament of Canada, 1981, p. 79)

The Obstacles Report reinforced the notion that all initiatives undertaken to address the

needs of people with disabilities ought to concern themselves with community.

Community was also a prominent concept internationally. For example, both IL

and CBR (as alternate approaches to the redress of disability problems) attempt to target

their disability education campaigns "at the community." Both also rely upon an

underlying "sense of community" to support their local initiatives. With respect to

CBR specifically, we read the following:

> Community based rehabilitation is emerging as a primary contender in the
> search for a practical and successful means of providing health care to a greater
> percentage of the disabled population. Its aims are to rehabilitate and train
> disabled individuals, as well as to find ways to *re-integrate them into their
> communities* [italics added]. (World Health Organization [WHO], 1981).

The IL position is similar. The World Programme of Action Concerning Disabled

Persons (UN, 1983) states their purpose is "to promote effective measures for

prevention of disability, rehabilitation and the realization of goals of full participation

of disabled people in social life and development, and of equality" (p. 1). As official

13

international disability policy statements however, the WHO and UN proclamations offer little practical guidance. Where is the "full participation of disabled people" meant to occur? How is human social life fully realized by people with disabilities? Could it be "in the community"?

At first glance it appears that community is implicated in these processes, and upon closer examination of disability policy this suspicion is confirmed. For example, Helander (1993) writes,

> Community-based rehabilitation is a strategy for enhancing the quality of life of disabled people by improving service delivery, by providing more equitable opportunities and by promoting and protecting their human rights.... At the community level, CBR is seen as a component of an integrated community development programme. It should be based on decisions taken by its members. It will rely as much as possible on the mobilisation of local resources. (p. 8)

Expanding upon the role of local disability organizations, the World Programme of Action stresses the vital contributions of people with disabilities themselves:

> The role of these organizations includes providing a voice of their own, identifying needs, expressing views on priorities, evaluating services and advocating change and public awareness.... In view of their vital importance in the process of participation, it is imperative that their development be encouraged (UN, 1983, p. 8).

As evident from these statements, the overall objective of the disability movement based on IL philosophy and CBR is directly related to community. Sometimes the word community is itself explicitly used to describe the aims and methods of IL and CBR. Other times, closely related words like participation, equality, development and

social life are used, thereby creating conceptual linkages between these ideas and community. At still other times, quite different phrases are used to generate community imagery. While "a voice of our own," for example, might not at first sound like it is related to community, it generates cognitive connections with fundamental ideas like democracy, self-determination and citizenship, that are related to the idea community. From the perspective of "language as persuasion" alone, this is sufficient reason to examine the discourse of community. However, there is a more compelling reason for doing so. That is because it is at the interface between ideology and practice that conditions for accessible, relevant and meaningful disability services are produced. If the language and imagery of community alters this context, then community represents so fundamental and formative a concept in the ideologies of IL and CBR that critical analysis is imperative.

## Social Action for Health

A final word about the reasons for studying the power of an idea such as community is warranted. Are the insights to be gained in the course of this analysis more widely applicable?

Disability was chosen as the specific context for this research because it offers the opportunity to explore the emergence of popular social action. As in many areas of health today, disability has seen a major resurgence of public interest, local knowledge and advocacy. If the results of this research focussed on the operations of ideologies provides insight into community formation and collective action more generally, then

study findings will hold value for all persons interested in promoting community based health initiatives.

One might reasonably think that the notion of community as a basis for a social movement of disabled people and a reorienting of professional rehabilitation services came about because of the inadequacies of traditional medical explanations for ill health and the weaknesses of professional, mostly institutional, remedies (Ife, 1995; Helander, 1993; WHO, 1982). However, a more nuanced explanation forces an evaluation of the emotional attractiveness of the notion of community itself. For instance, the idea persists that communities (whatever these are) provide a nurturing context for consciousness raising and personal development (Riger, 1993; Rissel, 1994; Holmes, 1993). Within such an "empowering" environment, a deeper understanding of the forces impacting on one's health are thought to emerge, thereby lessening feelings of powerless and contributing to a sense of control. In turn, this is believed to enhance health (Balcazar, Mathews, Francisco, Fawcett & Seekins, 1994; Cocks, 1994; Wallerstein, 1992). But does this actually occur? And most important here, is this what IL and CBR provide with their community based approach? Influenced by the notion of community, people with disabilities and rehabilitation professionals alike have expanded their understanding of disability and broadened their domains of expertise to encompass social and political issues, not only clinical and therapeutic matters. The idea of community is thus clearly a powerful force in the ideology and activities of IL and CBR.

In sum, the comparative framework of IL and CBR is an ideal way to study the

16

reciprocal impacts of widespread consumer activism and professional health services on the idea of community, and in turn, on the subsequent process of disability policy formulation. As Labonte has stated elsewhere (1994), understanding the reasons for increased public and professional involvement in community based health initiatives, as well as the precise strategies employed to define and control the forms of community participation generated by it, will have widespread implications within the realm of health and beyond.

## The Theoretical Framework

An analysis of the idea of community and its function within IL and CBR can best be elucidated by an approach that considers the social meanings of community. This approach necessitates close scrutiny of official ideological documentation, the viewpoints of critical informants, and also informal opportunities to observe the everyday practices of these groups. There are many competing interests and motivations within IL and CBR, including those of its most fervent ideological proponents and those for whom disability services are provided, people with disabilities themselves. The task of capturing these multiple perspectives is best accomplished from a theoretical perspective influenced by social constructivism. (see Figure 1, The Theoretical Framework)

17
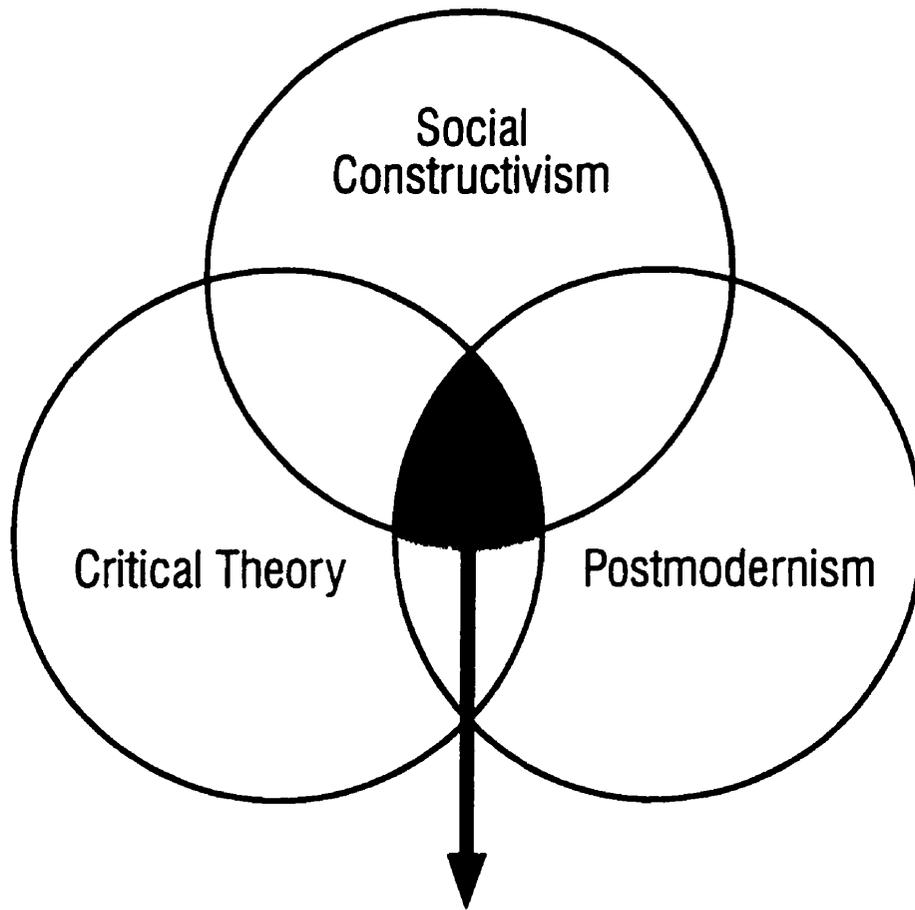
**CRITICAL POSTMODERNISM**

- contextual understanding
- normative foundation
- fundamental scepticism

Figure 1          The Theoretical Framework

18

## Social Constructivism

Social constructivism posits all knowledge is socially constructed. There is no "real" reality "out there" driven by immutable laws of nature (D. Harvey, 1990; Kellner, 1990). "Reality" is actually "multiple realities," contextualized by the lives of individuals whose experience life is. As it pertains to this research, social constructivism requires capturing the diverse perspectives of those participating in IL and CBR, as well as examining the widest possible breadth of program and social policy materials pertaining to IL and CBR. The scope of such an undertaking is considerable, especially because for social constructivism knowledge creation is the product of consensual and interactive inquiry (Morrow, 1994). This approach takes time, as interpretations must repeatedly pass through a researcher-participant feedback loop until agreement on the meaning of information is reached.

For the constructivist researcher, the process of knowledge creation is not only lengthy, it is also delicate. Again, this is because of what knowledge is. In stark contrast to positivism where the "building blocks of science" are summarized in time-stripped and context-free generalizations (Morrow, 1991), social constructivism holds to a subjectivist epistemology. In Lincoln's (1992a) words,

> The inquirer and the inquired-into are merged into a single, interactive entity, and findings that result from the inquiry are *literally* created by the interaction between the researcher and the researched. The traditional ontology/ epistemology distinction is not only challenged but effectively disappears.
> (p. 380)

Constructivist researchers must also be cognizant of their own personal influence on the

knowledge creation process. The researcher must be reflexive, that is, be aware, as Denzin (1994) puts it, of the steps that take us "from field to text to reader" (p. 501). Altheide and Johnson (1994) have examined reflexivity in some detail, and define it as the self-conscious and ongoing awareness "that the scientific observer is part and parcel of the setting, context, and culture he or she is trying to understand and represent" (p. 486). In an intricate and iterative dialectic of analysis, critique and reanalysis, the researcher must simultaneously preserve, coherently integrate and represent multiple knowledge perspectives.

Methodological challenges aside, the advantage of a social constructivist approach is that it takes apart (i.e., deconstructs) the phenomenon of interest revealing contradictions, ambiguities, values and interests suppressed far beneath the surface of the positivist's "facts" (Agger, 1991; L. Harvey, 1990). This approach therefore offers the opportunity to discover how values and motivations, culture and experience contribute to our understanding of social groups (Krefting, 1990; Yach, 1992). It also offers the possibility of observing the complicated ways in which social, historical and political processes mediate this process (Baum, 1995; McKinlay, 1993). Since human health is intricately tied to the hopes, beliefs and understandings of individuals, the constructivist paradigm offers significant potential for health and disability research.

There are, however, significant drawbacks to a theoretical framework wholly committed to social constructivism (Morrow, 1994). First, the question of power is largely ignored because constructivists exclude the analysis of socioeconomic structures and refuse to engage the idea of causality. Second, there is the potential danger of

20

infinite regress into expressions of difference. The constructivist's unwillingness to assign superior status to any one of the many "multiple voices" virtually precludes any "correct" point of view, rendering the determination of useful social insights and formulation of policy recommendations problematical. Third, constructivists exempt methodology from their critique. But as Morrow (1994) points out, the assumptions upon which our theoretical frameworks are grounded have direct implications for selection of research questions, topics and methods. He writes, "Methodology is ... inevitably *prescriptive* because it attempts to legitimate the use of particular methods in ways that are consistent with the development of the specific theory in question" (p. 36). For this reason precisely the thesis research, originally conceived as a conventional ethnography of IL and CBR programs, evolved into a study of much broader theoretical proportions.

## Critical Theory

In its broadest sense, critical theory sees social phenomena as related to other phenomena within a prevailing social structure maintained through the exercise of political and economic power (L. Harvey, 1990). Such power is legitimated through ideology. At its core, critical theory is concerned with unveiling this ideological mystification. While the differential delivery and impact of IL and CBR programs could have been studied as a comparative ethnography guiding by social constructivism, investigating the idea of community in IL and CBR, and understanding IL and CBR as ideology could not. Thus, critical theory with its emphasis on ideological critique was

investigated as a guiding frame.

Critical theory is often associated with the so-called Frankfurt School, a term

which refers to the work of members of the Institute for Social Research established in

Frankfurt, Germany in 1923 (Kellner, 1990). Horkheimer, Fromm and Marcuse, and

later, Adorno and Neumann, were some of its most talented theorists. The purpose of

the Institute was to elucidate "the fate of human beings, insofar as they are parts of a

community, and not mere individuals. It concerns itself above all with the social life of

people: state, law, economy, religion, in short, with the entire material and spiritual

culture of humanity" (Horkheimer, in Kellner, 1990, p. 13). Importantly, the original

project of critical theory was supradisciplinary. It represented an attempt to involve

researchers from various disciplines in the construction of a historical and systematic

theory of contemporary society. This methodology therefore "locates" specific

phenomena in historical context and is intent upon analysing its ideological

manifestations and processes (L. Harvey, 1990).

Critical theory is an important influence on this research because it endeavours

to be a form of social or cultural criticism. Many of the basic assumptions of critical

theory are therefore shared by this research, including

> that all thought is fundamentally mediated by power relations that are social and
> historically constituted; that facts can never be isolated from the domain of
> values or removed from some form of ideological inscription; that the
> relationship between concept and object and between signifier and signified is
> never stable or fixed and is often mediated by the social relations of capitalist
> production and consumption; that language is central to the formation of
> subjectivity (conscious and unconscious awareness). (Kincheloe & McLaren,
> 1994, p. 139-140)

22

With critical theory as a guide then, the structural features of IL and CBR are subject to scrutiny. Issues such as professional power and elite consumer control of the disability agenda, for example, can be engaged. In addition, and unlike social constructivism, critical theory does not exempt methodology from its critique. Critical theory acknowledges that "knowledge of the context and conditions in which particular research findings are produced can be relevant to their evaluation and ultimate validation" (Morrow, 1994, p. 236). Since all of our skills and knowledge are grounded in, and only become possible through, our experiences and prejudices, denying them or suppressing them can only distort the pursuit of knowledge.

While critical theory informs the thesis research, it is not entirely beholden to it. One of the fundamental tenets of critical theory is that it aspires to confront social injustice and aim for a better world. In its classical sense, critical theory is deeply rooted in the Marxist tradition which sought to shape the consciousness of the working class (D. Harvey, 1990). Strong versions of critical theory advocate political transformation. This research, while critical and reflexive, is distinctly nonprescriptive in orientation. It is not committed to a participatory action framework of research, for example. Nor does it make any radical claims about its power to transform society.

As a brief aside, it is important to acknowledge that participation in research is seen to be of particular significance in situations where research is conducted within disadvantaged contexts as disability might be considered to be. The problem, simply put, is that people with disabilities are historically thought to have been neglected with respect to participation in and development of research that pertains to them as a group

23

(Krogh & Petric, 1994). The claim is that traditional research procedures have oppressed disabled people, reducing them to passive objects. Oliver (1990), for example, states: "Disabled people have felt victimized by professionals.... For those reasons more and more disabled people are refusing to participate in research over which they have no control and which they regard likely to further their oppression" (p. 7-9). This concern is well known to the author. It is therefore incumbent upon her to include the subjects of the research in the research process. Both a social constructivist and a critical theory approach permit (or require) this, although in different ways. A constructivist approach, attentive to the "various voices" of people with disabilities, goes some distance in addressing this problem (Ferguson, 1985; Lincoln, 1992b). A critical theory approach, concerned as it is with the transformation of oppressive forces, does so as well (Liggett, 1988). Whether the researcher becomes a "passionate participant" (constructivism) or a "transformative intellectual" (critical theory), the researcher has an explicit responsibility to those researched (Guba & Lincoln, 1994).

The thesis research, while not emancipatory, does aim to address the issue of research participation. The researcher participated alongside people with disabilities in local consumer movement meetings and national conferences focussed on the disability movement and the IL philosophy, for example. Presentations and papers were developed in conjunction with disabled consumers and targeted at that audience. In all of these instances, the perspectives of disability spokespersons were deliberately sought and emphasized in the production of written materials (Lysack, 1996b & 1996c; Lysack & Kaufert, 1994a). On occasion, these collaborative efforts culminated in short

24

articles published in consumer-orientated magazines (Lysack, 1996d). Other papers

reached an international IL and CBR audience (Lysack, 1996a; Lysack & Kaufert,

1996).

While critical theory is admittedly a very important influence on the research,

one aspect of the approach presents some difficulty. In short, its commitment to social

transformation means that certain basic premises of IL and CBR cannot be easily

examined. For example, people working to improve the quality of life for people with

disabilities (i.e., IL and CBR advocates), do not appreciate having the legitimacy of

their cause questioned. The motivations for participation in IL and CBR are not easily

challenged either. A close adherence to critical theory prevents the researcher from

asking the central question: Is the cause, aims, purpose, ideals, activities, motivations

and ideology of IL and CBR legitimate? If a classical critical theory approach was

adopted it would commit the researcher to seeing the oppression of people with

disabilities as a given, and the respective missions of IL and CBR as right and good.

It must be emphatically stated that the researcher is aware of the reasons why

people with disabilities are struggling to achieve equality viz a viz dominant society. In

addition, she stands solidly behind their efforts. However, there is still a need to stand

back from this issue (i.e., not wholly embrace critical theory) in order to achieve the

thesis purpose. An approach that demands complete commitment to the emancipation

of people with disabilities leaves no room for a comparison of the sometimes competing

claims of disabled people and other disadvantaged communities, the claims of disabled

people and dominant society, or even that the claims of people with disabilities can be

25

viewed as ideology. This poses a serious problem for the research because it is interested in the idea of community and its role in IL and CBR ideology. A perspective that accepts the notion of community as asserted by a particular community leaves no room for critical analysis of this concept, or more broadly, a critique of any aspect of IL or CBR whatsoever.

## Postmodernism

The third and final theoretical influence on the research is postmodernism. Postmodernism is not easily encapsulated in one phrase or idea, but is rather an amalgam of ideas put forward by a number of scholars. David Harvey (1995), in his brilliant book, *The Condition of Postmodernity*, describes how an interweaving of many intellectual traditions resulted in this eclectic tapestry of philosophical thought that encompasses the arts, literature, economics, architecture, philosophy and science.

Rosenau (1992) has examined community health organizing specifically, and has provided a useful summary of postmodernism's key elements. She describes postmodernism as profoundly sceptical of reason and truth and deeply suspicious of authority and expertise. Postmodern thinking has no room for essentialist thinking which tends to treat historical and social constructions as fixed, natural and absolute. Rejecting all "grand narratives" and "logocentric worldviews" as Sardar (1992) also notes, postmodernity encourages a reconsideration of personal knowledge, with radical versions claiming no moral universals whatsoever, only subjectivism, and interpretation.

26

This research adopts a more moderate position. Like Sardar (1992) and Sui (1994), this research takes postmodernism to represent a new critical sensibility that involves a heightened scepticism about truth claims and how they are represented. As it pertains to this study, the major advantage of a postmodern approach is this preservation of scepticism. The postmodern researcher is distrustful of authority and expert opinions, and does not privilege one account of reality over another. The postmodern researcher suspects all truth claims as masking and serving particular interests in local, cultural and political struggles. Finally, and because of postmodernism's concern with language and meaning, it becomes possible to analyze IL and CBR as discourse. While not constituting a proper discourse analysis (Lupton, 1992), a postmodern approach still attends to the rhetorical devices and structures of discourse, that is, to the style as well as the subject matter of communication, and the manner in which ideology is reproduced in them. There is thus considerable attractiveness in adopting a postmodern theoretical approach for research focussed on the purpose of the language and imagery of community in the international discourse of IL and CBR.

As with constructivism and critical theory, embracing a radical version of postmodernism also creates a special set of problems in the case of disability research. First, it may be that personal visceral experience is extinguished. As DiGiacomo (1992) notes, in the mandatory reduction of experience to text, "the politics of language is the central concern and reduces living, ill, or dying persons to footnotes" (p. 125). Second, and in this way similar to social constructivism's subjectivism, the postmodern

27

critique is vulnerable to nihilism and inaction (Marwick, 1995; Rosenau, 1992). This is a serious problem as this thesis research endeavours to provide some guidance with respect to the development of disability policy. A pure postmodern approach would shun prescription, however. Therefore, the unique strengths of social constructivism, postmodernism and critical theory were combined, bringing together contextual understanding, scepticism, critical reflection and a normative foundation. The label applied to this hybrid of theoretical strength is critical postmodernism.

## The Social Context for the Research

Generally speaking, all research in the critical tradition takes the form of self-conscious criticism. In other words, the researcher is aware of the ideological and epistemological imperatives which influence her work at the same time that she is aware of their subjective interpretations and normative claims. It is therefore crucial to detail the social context of the research and the researcher's relationship to those researched (Atkinson, 1990).

An exploratory qualitative study of Indonesian women's volunteerism in CBR was the focus of the author's Master's research (Lysack, 1992). Interest in the community as a place of social power originated during these studies and has only deepened since that time (Lysack, 1995; Lysack, 1996a). The researcher has participated in national and international conferences on this topic, and during the course of this doctoral research, has become a volunteer for a disability advocacy organization. The author is also an occupational therapist. Although not currently in

28

clinical practice, her contact with the profession continues through scholarly activities with clinical and academic colleagues and informal personal networks. These relationships provide ample room for role conflict and cross-cutting loyalties. The reflexive researcher must be ever vigilant to sufficiently appreciate and account for their influence upon the entire research process.

Gaining access to the network of international disability researchers, disabled people's organizations (DPOs) and the sub-group of rehabilitation professionals active in CBR was imperative for this research. Although the author was relatively well known to key international IL and CBR leaders and spokespersons, significant effort was nonetheless necessary to identify new contacts, locate unpublished documents and establish rapport and trust. This process was particularly crucial to gaining access to disability activists. The number of people engaged in the international disability field is relatively small and it is acknowledged that the IL and CBR informants in this study reflect the researcher's even smaller network of contacts. There are also historical tensions between certain IL and CBR representatives. Access to research materials and informants, and ultimately the development of credible study findings, were therefore highly dependent upon the level of respect the researcher was able to earn, as well as upon her discretion, diplomacy, perceived fairness, sensitivity and availability.

## Organization of the Thesis

This first chapter of the thesis has set out the study purpose and argued for its importance. This Chapter has also discussed in some detail the theoretical framework

guiding the research. The remainder of the thesis is presented in the following way:

Chapter 2, Assertions of Community and Disability, provides the historical dimension

to the research. The analyses contained in Chapter 2 illustrates the ongoing evolution

in the meaning of community and disability and examines the specific forces that impact

upon this evolution. This background is essential to a complete understanding of the

development of IL and CBR and their respective community based approaches to

disability. Chapter 3, Study Design, Methods and Analysis, details the mechanics of

the research process. Specific information about research sites, research data, ethics

and study limitations is provided here. Chapters 4 and 5 provide the empirical data to

substantiate the overall argument about the use and purpose of community language in

IL and CBR. Representing Community (Chapter 4) focuses on the distinction between

IL and CBR with respect to the meaning of community, showing that for IL,

community is based upon identity, while for CBR, community is geographical.

Community and its Discontents (Chapter 5) deepens the analysis of community,

focussing in more specific detail on the problems associated with assertions of

community. Chapter 6, The Good Society, concludes the thesis research. This chapter

summarizes study findings and discusses their implications for social policy formulation

and theory development. In its entirety, this research is offered as a modest

contribution to both the theoretical debate about, and the practical realities of,

communities in action for health.

# ASSERTIONS OF COMMUNITY AND DISABILITY

## Introduction

The purpose of this chapter is to describe the evolution in the meaning of

community and describe IL and CBR, two community-based approaches to international

disability. The chapter is divided into four major sections and proceeds as follows:

First, the ubiquity of community language is demonstrated, drawing on evidence from

the disability and international health policy contexts. Second, the meaning of

community is explored. This section includes a review of the sociological and

historical origins of this concept and describes a distinctive turn in its contemporary

usage. In the third section, the historical development of the meaning of disability is

examined. This includes a discussion of the historical attitudes toward and treatment of

disabled people in the North as well as the South. The final section of the chapter

describes the historical emergence of professional rehabilitation and the disability

movement. This review of the literature is a necessary prerequisite to an investigation

of the idea of community in IL and CBR.

## The Language of Community

At Alma-Ata in 1978, the WHO made the landmark Declaration of Health for

All By The Year 2000 (WHO, 1978). This proclamation launched an unprecedented

international revival of interest in wellness, prevention of illness and local control of

services to improve people's health (Brownlea, 1987; WHO, 1975 & 1981). The

31

Declaration formally alerted the health services sector in many countries that physician care and hospital programs were inadequate to address the stated health needs and interests of its citizens. Rather, attainment of good health was thought to center on concepts with an underlying democratic vision, concepts like community participation, empowerment, health promotion and collective action. The health challenges identified and the strategies proposed to remedy these, spoke of reducing inequities, enhancing coping, fostering mutual aid, supporting healthy environments and generating healthy public policies (Charles & DeMaio, 1993; DeJong, 1993; Hancock, 1993; Stevenson & Burke, 1992). Integral to these ideas was the concept of community.

## Community and International Health Policy

The Alma-Ata Declaration had global ramifications. It was, for example, a critical influence on the Ottawa Charter on Health Promotion (WHO/Health and Welfare Canada/The Canadian Public Health Association, 1986). Canada was intimately involved in the drafting of the Ottawa Charter which moved health policy one step further in its orientation toward integrated solutions to personal and population health problems. The Ottawa Charter states as priorities creating supportive environments and strengthening community action. With respect to the former, we read as follows:

> Our societies are complex and interrelated. Health cannot be separated from other goals. The inextricable links between people and their environment constitutes a basis for a socio-ecological approach for health. The overall guiding principles for the world, nations, regions and communities alike, is the

need to encourage reciprocal maintenance -- to take care of each other, our communities and our natural environment. (p. 426)

The Ottawa Charter is also explicit in its commitment to community action. Here too, the idea of community is prominent.

Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities, their ownership and control of their own destinies. Community development draws on existing human and materials resources in the community to enhance self-help and social support, and to develop flexible systems for strengthening public participation and direction of health matters. (p. 427)

Unfortunately, these health policy documents contain no analysis of the community concept. If community is a place, we are not told where to find it. If community is a feeling or a sentiment, we are not told what emotions characterize it, let alone how to strengthen it. Thus, constituencies and their representatives are left to interpret community in the way they see fit. The unfortunate outcome is that people have different understandings of what community is, or they mistakenly assume a shared understanding when they in fact have none. Either way, significant problems emerge. For example, the nature or features of real communities cannot be discerned. Furthermore, few worthwhile recommendations about the community can be formulated if the dissonance between the features of communities described and the features that exist are too substantial. Despite the importance attached to the concept and its persistent use in international health, it is striking how little sustained examination of community has occurred.

33

As a formative ideological principle, community has been embraced by governments, health professionals and nonprofessionals alike. While seemingly competitors for social resources, these groups all appear to find in community an attractive and useful idea. Community can be used to describe the reorientation of state funded and professionally delivered rehabilitation services, and similarly, to describe the social advocacy activities of movements like that of disabled people. How does a situation like this arise?

Perhaps the utility of community is related to the widespread perception that community implies advantage. One of the more intriguing aspects of community is the intuitive sense that it is a good thing that has always been there, and that somehow, modern life has rendered us incapable of capitalizing upon its benefits (Heller, 1989). McKnight (1987 & 1994), for example, defines community as a flexible structure which recognizes human fallibility and provides opportunity for experimentation and learning. Claiming that communities are not vested in dominance or hierarchical relations, McKnight says community affiliation ensures diversity, creativity and consensus. Heller (1989) adds that community gives expression to our "needs for intimacy, diversity, usefulness, and belonging" (p. 4). Walzer (1994) states: "It is only in the context of associational activity that individuals learn to deliberate, argue, make decisions, and take responsibility" (p. 189). Most outspoken about the rewards of community is Amitai Etzioni (1993) who says community association strengthens the very "moral infrastructure" of society (p. 142). The extent to which communities of any sort actually possess such qualities, however, is a matter for empirical

34

investigation. The important point here is that community is a powerful and strategically useful word.

## The Goodness of Community

The attractiveness of community must be attributed, at least in part, to its apparent goodness. At first glance, this goodness seems related to a romantic vision of the past, an enchantment with the primitive and natural. Nearly 20 years after the Declaration of Health for All however, Jewkes and Murcott (1996) state that incredulously, community has been naively "assumed to be a coherent unit, whose members would operate together for shared purposes" (p. 558). But the near absence of analysis of the concept of community in health necessarily means that conceptual ambiguities and problems abound. While we might expect the word to be as value-neutral as other terms of social organization like state, nation, and society, we observe that community seems never to be used unfavourably. Community typically connotes something socially good and constructive which should be supported and sustained (Butchart & Seedat, 1990; Hawe, 1994).

"Community the good" has certainly taken root in health. Labonte (1989) asserts that community has become an essential adjective to every health program. This is not a phenomena restricted to the West. Writing about his experience in Southeast Asia, Woelk (1992) states "project proposals are more likely to be approved and funded, if the phrase `community participation' appears at least *somewhere* in the text" (p. 419). In contrast to the ills of society, community is believed to be the repository of

35

all happiness and security. While certain aspects of contemporary community seem to differ from that of traditional community, the positive connotations persist. Berger (1988) captures the enchanted dichotomy this way:

> In the literature of sociology the concept of community has, since the nineteenth century, been contrasted with the ideal of society. Community is tradition; society is change. Community is feeling; society is rationality. Community is female; society is male. Community is warm and wet and intimate; society is cold and dry and formal. Community is love; society is, well, business.
> (p. 50)

Thus, when we distinguish community from state or society, we elicit powerful mental images, whether we are aware of it or not.

The preponderance of positive community language may not merely represent unthoughtful and naive usage. A more nuanced explanation is that the word community can be strategically asserted to achieve explicit goals. The ephemeral and fluid nature of the community concept makes it an ideal word to use in occasions calling for ambiguity, diplomacy and persuasion. Still, the possibility that the emergence of the notion of community signifies a real and deepening collective public concern for health should not be dismissed prematurely. It may signal a genuinely new direction in health organizing. However, the preponderance of community language may also represent "a widening of the professional gaze," as Foucault (1965) calls it -- an expansion, and not reduction, of professional domination and state control; a public abandonment of traditional domains of responsibility and not the reverse. The following section explores these possibilities. And the analysis supports our growing realization that community is a complex and powerful force.

36

### The Sociological Origins of Community

With the ubiquity of community language and its goodness established, the stage
is now set for a more detailed examination of the origins of the community concept.

Community as a formal construct in philosophical thinking likely emerged in the
latter part of the 19th century during the Enlightenment (Bell & Newby, 1971). The
hallmark of this period in European history was the primacy of rationality. The
Enlightenment took human rationality as an article of faith, as period philosophers
assumed human reason was the vehicle that would lead to progressive social change,
the means by which people would "throw off their chains."

Not everyone was enamoured with the rational and mechanistic world view of
the Enlightenment. The German Romantic Movement, propelled by its two most
prominent proponents, Herder and Goethe, argued that the true human quest is for free,
creative expression, not "empty rationality" (Koch, 1993). Emerging in the mid-1880s,
the Romantic Movement therefore challenged the primacy of the rational mind as the
best path to knowledge. They saw the rational-scientific ontology of the dawning
European industrial age as negating the emotional character of life. The Romantics
deemed this an affront to human essence and resisted it.

The Romantic Movement's ideas were perpetuated by such intellectuals as
Comte, Weber, Tönnies, Marx and Durkheim, some of sociology's most eminent
founding fathers, and it is at the dawning of the twentieth century that the origins of the
modern idea of community are commonly traced. These thinkers saw, in the expansion
of industrialization and growing urbanization, a negative social force, the dark side of

37

the industrial revolution -- the rupture of traditional ties to village, family, church and guild. Their views provide a useful starting point for a discussion of community.

Community, viewed by Auguste Comte, was man's natural habitat. Comte lamented what he saw as a breakdown of the traditional and the alienation of mankind. Emile Durkheim too feared disintegration of social relations into "anomie," a state of normlessness where there was complete social breakdown. They believed the upheavals of industrialization would give these feelings full rein:

> Industrial society -- and its ecological derivative, the city -- was typified by competition, conflict, utility and contractual relations; community -- and its ecological derivative, the village or at the most, the small town -- was the antithesis of these. The impersonality and anonymity of industrial society were highlighted by reference to the close personal ties of the community. (Bell & Newby, 1971, p. 22).

To Max Weber too, the world was moving toward "mechanized petrification" by hierarchical administrators and control by the "rational machine" known as bureaucracy. In this essentially modern condition, individual worth was lost; the individual was turned into a cog in the social machine (Koch, 1993). Because their "ties of community" consisted of "images of the good life," as Bell and Newby (1971) report, community's perceived passing "was to be deplored, feared and regretted" (p. 21-22).

If a prominent historical father of community can be identified it is likely Ferdinand Tönnies who formalized much of the earlier sociological thinking about community (Adair-Toteff, 1995; Tönnies, 1957). In his book *Gemeinschaft and*

38

*Gessellschaft* (Community and Society) published in 1887, Tönnies distinguished

Gessellschaft, the large-scale, impersonal and contractual ties that were seen to be on

the increase with capitalism, from Gemeinschaft, thought to be the home of all virtue

and morality. In Gemeinschaft, Tönnies wrote, members were relatively homogenous

and immobile in social and geographical ways. Their human relationships were

intimate and enduring based on who people were rather than what they achieved.

Community in this sense meant more than local geographical community, it

encompassed religion, work, family and culture. It referred to social bonds

characterized by emotional cohesion, depth, continuity and fullness. At the very core

of community was the sentimental attachment to the conventions and mores of a

beloved place and its people (Tönnies, 1957).

The turn of the twentieth century represented the zenith of community study.

By the mid-1900s, as Day and Murdoch (1993) report, the concept of community was

largely discarded from the vocabulary of sociologists, except in smaller and related

fields like community development.

> (Community) was seen as inherently bound up with a discredited functionalism,
> which resulted in an excessively integrated mode of analysis leading to a reified
> concept of community as an active social entity. This tended to be accompanied
> by a conservative consensualism which subordinated all groups and individuals
> to these communities.... Community was generally agreed to be a confused and
> chaotic concept, impossible to define clearly, and carrying all sorts of dangerous
> and unacknowledged cargo.... Bell and Newby's textbook account of this
> tradition (1971) turned out to be, in effect, its death knell. (Day & Murdoch,
> 1993, 83-84)

The absence of community in sociology from 1960 to 1990 and the charge that

community studies were seen to commit the "heinous crime of spatial determinism" (Day & Murdoch, 1993), meant that the concept all but disappeared. The absence of community as a guiding theoretical construct in sociology did not mean community was not a formative concept elsewhere however. Most noteworthy was its appearance and persistence in international community development.

## International Community Development

The term community development came into popular use after World War II, supplanting such terms as mass education, village improvement and rural development. Village level workers were the backbones of these program at the local level (WHO, 1977). The earliest community development efforts consisted mostly of small-scale projects, frequently administered and supported by church groups and other reformist organizations, or were undertaken in cooperation with universities or regional development organizations.

Community development expanded rapidly in the 1950s, in great part due to its political endorsement by the U.S. government. The scope of those development projects varied widely. The Rockefeller and Ford Foundations, for example, were frequent sponsors of small-scale crop cultivation projects and industry cooperatives. The kind of community development exemplified by these initiatives is best described as self-help. At the other end of the spectrum were huge agencies like the UN and World Bank, where community development often meant technical assistance for nation-wide irrigation and transportation networks (Christenson & Robinson, 1989).

The international community development movement had reached its peak by 1960 and most community development programs were faltering by 1965. Dramatic reductions in funding from donors and disillusionment with the performance of many community development projects were the primary reasons for its decline (WHO, 1977). Voth and Brewster (1989) add that the decline can also be partially attributed to problems which persisted between the technical and self-help aspects of community development. Once American support for large-scale, publicly supported international projects began to wane, it was apparent that community development at least on a large scale would disappear. As practised by churches and NGOs from which it originated, community development continues to be a widely used and viable strategy in many Southern countries.

Why was community development a strategy specifically targeted at the South? Some have concluded that the primitive view of naturally occurring communities dovetailed nicely with the economic reality of severely limited fiscal resources in the South (Foster, 1982; Woelk, 1992). Rifken (1985) and Stone (1992) argue that local governments saw in community participation the most cost-effective alternative to approaches that would draw heavily on scarce state resources. Thus, community projects replaced institutional ones when the necessary capital to fund the latter was lacking. More cynical however, is Rahnema (1990), who asks whether the West expected to find community more often and more easily in the South because it views the South as less tainted by industrialization, more natural and primordial. Do predominantly rural communities whose members share a common history, culture and

41

religion present the ideal opportunity for implementation of so-called development projects? Are we "exporting our nostalgia" to borrow a phrase from Cameron and Gatewood (1994)?

Even more critical is Esteva (1992) who writes that the ideas of development and modernity are undeniably intertwined. Modernity is the association of truth with the dominant culture's perspective, and the appropriation of the history of other cultures under its own. It can do this because privileged knowledge of the direction of change is claimed by those who declare themselves furthest advanced along its course (Sachs, 1992). Development too always implies a favourable change, a step from the simple to the complex, from worse to better, just as modernity implies progress from the primitive. Development in this context is a reminder of an undesirable undignified condition which effectively provides two-thirds of the people on earth with a reminder of what they are not (Sachs, 1992). However, as Young (1990) states, these categories inappropriately perpetuate an inside/outside distinction that not only emphasizes exclusion but also implies that one side is inferior to the other. "One side designates the pure, authentic, good, and the other the impure, inauthentic, bad (p. 303).

Health is not unaffected by this sort of modern thinking about development. In fact, health may be a "carrier of modernity," intimately shaping the views of people's relative underdevelopment and compelling them to "catch up." As Escobar (1992) suggests, by participating in health projects affiliated with the West/North comes the sense of advancing into the modern. Nanavatty (1988), in his review of the Southeast Asian situation, agrees. He further argues however, that the entire process of Western

42

economic development created further class and caste (i.e., community) conflict, not less. "The critical poor" were never involved in any way, and furthermore, vested interests within the country "got a free hand to usurp the resources of development in its own interests, rather than sharing the fruits of development with the deprived and neglected sector of local communities" (Nanavatty, 1988, p. 97). Nanavatty's pessimistic conclusion is that due to the co-potation of community and participation, the potential advantages of development were never fully realized.

Recent evaluations of the WHO's strategy for decentralization of health services and community participation in health confirm Nanavatty's point of view (Rathwell, 1992; Rondinelli, Nellis & Cheema, 1983). These authors and others argue that, in the South, the ideal of achieving development through the processes of community participation and empowerment has not been successful (Drake, 1992; Eldridge, 1984). The major roadblocks to community health project success continue to include: threats to professional status/expertise (Green, 1991); top-heavy and inefficient bureaucracies (Foster, 1987); governments with much higher national priorities (Lele, 1993; WHO, 1991); and finally, corruption as powerful elite interests capture the mechanisms of community participation and empowerment to further their own personal goals (Collins & Green, 1994). The most radical scholars in the South challenge the very idea of development itself, seeing little in development but exploitation by the West (Alvares, 1992; Escobar, 1992; Esteva, 1985; Marglin & Marglin, 1990; Nandy, 1990).

Community is indeed a complex and multi-faceted concept. On the one hand, a

43

modern perspective views communities in the South as undeveloped and inferior. But

on the other hand, the community is also seen to be an important repository for unique

knowledge about local conditions. Hence, the community can be viewed as primitive

and inferior, or alternatively, as primitive and ideal, embodying the characteristics and

traditions of traditional community apparently absent and certainly lamented in the

North.

## Contemporary Community and the Idea of Empowerment

In contrast to the elements of goodness and predictability thought to be

characteristic of communities in the Southern context and of the historical past

everywhere, the contemporary vision of community appears to be one of immediacy

and choice. While it might be said that in former times and far away places people

were born into communities, today community status is essentially chosen. Elshtain

(1993) and Walzer (1994) assert that contemporary society is also characterized by a

general loss of public confidence in government and the representativeness of the

democratic system. Within such a context, the idea of community has become deeply

individualistic and minimalist. Contemporary community affiliation is also somewhat

fleeting as multiple communities jostle for the attention of the individual. In contrast to

traditional community members' devotion to a shared community purpose, individuals

in contemporary communities tend to sever their ties when the group no longer meets

their needs. As Berger (1988) says,

44

In the postindustrial world our quests for freedom and alternatives mean that we share the minimum culture necessary for social order; we ideologically disagree about the rest, and bring to bear our highly differentiated, particular and segmented subcommunities in political struggles over what we are obliged and constrained to accept and what we are free to choose, dissent from, and rebel against. (p. 52)

In her recent review of community health organizing, Rosenau (1992) expresses doubt about whether something called community can even exist in the contemporary era "where society is fragmented and personal identity is diffuse and changing" (p. 311). Rosenau also states the public is sceptical about the intentions and motivations of so-called communities, considering many oppressive and a threat to personal privacy. In contrast to the notion of community as commitment and responsibility to the group then, the purpose of many traditional communities, the modern view of community appears to have as central a growing sense of personal entitlement. The purpose of community today therefore is not so much to protect some traditional values as it is to band together in large enough numbers that the fight for individual rights will be recognized.

Also important in the discussion of contemporary community is the concept of empowerment. Empowerment may provide the mechanism by which the benefits thought present in community actually accrue.

The historical origins of empowerment rest with grassroots community development projects which initiated the idea that empowerment consists of a basic struggle and confrontation with those wielding power (Alinsky, 1969; Freire, 1971). In contemporary use, empowerment has retained this element of confrontation, but the

45

term is also used in rather vague ways to indicate some sort of good social process (Grace, 1991; Rissel, 1994). Contemporary definitions also tend to focus on empowerment's consensual aspects, for example human rights and abilities, as opposed to deficits and needs, thereby encouraging nonconflictual goals such as learning and personal growth (Rappaport, 1987). It is in this sense that empowerment has found itself at the heart of a widespread trend towards greater control by citizens in many areas of health, including medicine (Illich, 1976 & 1977) and the self-help movement (Rappaport, 1985). The promise of empowerment is that through enhanced group capacity, disadvantaged groups will improve their status relative to more powerful groups in society.

While the idea of empowerment as self-determination and collective power may be traced to the civil rights and community development activities of the 1960s, the word itself has only become prominent more recently (McLean, 1995; Zimmerman, 1990). In the Lalonde era in Canada, for example, health policy was typically formulated in terms of individual determinism. Individual efforts enhanced health, not group efforts. As the broader social determinants of health became recognized however, the word empowerment came to the fore. Regrettably though, and like community, empowerment is ill-defined, both as a concept and as a process (Israel, Checkoway, Schulz & Zimmerman, 1994; Labonte, 1996; Riger, 1993). In the Ottawa Charter on Health Promotion, for example, empowerment is equated simply with enabling people to increase their ownership and control over their own endeavours and destinies. At least as it relates to health, empowerment has also been variously

46

interpreted as enhancing personal growth (Keiffer, 1984), increasing feelings of control

and mastery over one's life (Rappaport, 1987; Zimmerman, 1990), and improving

personal competence and self-esteem (Lord & Hutchison, 1993). But empowerment is

also used in ways that conflate feelings about personal efficacy or self-esteem with that

of actual decision-making control over societal health resources. As Rissel (1994)

notes,

> The ambiguity surrounding the concept is a major stumbling block for the field.
> Being practical and problem oriented, and largely atheoretical, health promotion
> (and public health) tends to borrow somewhat haphazardly from more theory-
> based disciplines such as political science, psychology and sociology. As a
> result, theory laden terms are used in health promotion without considering the
> tradition behind these terms -- empowerment being one of the latest in fashion.
> (p. 39)

This haphazard borrowing or, more cynically, stripping the intellectual context of

empowerment (Grace, 1991; Stevenson & Burke, 1992) has several consequences.

For example, use of the term empowerment may disguise "top-down" implementation

of so-called participatory programs. The Ottawa Charter, for example, acknowledges

social inequalities and challenges professional control of health, but it stops short of

calling for major political change. This leaves the door open for an expansion of the

rhetoric of participation and empowerment without a meaningful transfer of power.

A vague meaning of empowerment coupled with the amoeba-like quality of

community leads to a second significant problem (Wallerstein, 1992). Who exactly is

empowered -- communities or individuals? Does empowerment mean that some

individuals or groups gain at the expense of others? If empowerment really implies a

fundamental redistribution of resources within a particular social group or within a given geographical location (a community?), then some people will benefit and others will not.

A third problem is that at their core, empowerment and community may be at odds (Riger, 1993). As Riger (1993) asks: "Does empowerment of disenfranchised people and groups simultaneously bring about a greater sense of community and strengthen the ties that hold our society together, or does it promote certain individuals or groups at the expense of others, increasing competitiveness and lack of cohesion?" (p. 290) Riger concludes that the essence of empowerment is autonomy and conflict rather than cooperation among groups and individuals, control rather than communion and connectedness. Paradoxically then, situations which foster community may be the opposite of those which foster empowerment. When interdependence is no longer necessary, then the psychological sense of community may disappear as well. This may explain, in part, both the drive to be part of a community (to be empowered) and the fragmentation of communities (because of competition between communities).

## The Features of Traditional and Contemporary Community

The foregoing review of the literature suggests that a distinct shift has taken place in the meaning of community. In short, it seems that because contemporary communities seem to have lost many of the positive characteristics thought connected to traditional communities, then the idea of community has been altered as well. A brief review of the features of community believed lost in contemporary times is therefore in

48

order.

The image of traditional community includes a geographical dimension where personal relations between community members are grounded in locality. Members are well known to each other and they are loyal, both to each other and the goals of the community as a whole. When forced to choose however, members of traditional communities place the needs of the group ahead of their own. The traditional community is also a place where the majority of people's needs are met. As a result, the community is relatively homogenous. Sharing a similar socioeconomic background or ethnic heritage and frequently holding similar social values, traditional community is an harmonious and equitable place where reciprocity prevails. Traditional community is a good place where individuals contribute to the welfare of others during good times, but can be assured of protection in times of need.

Contemporary communities stand out in sharp relief against the traditional image of communities past. Contemporary communities need not be anchored in physical locality, nor do they require face-to-face relations. They can exist free of conventional time and space limitations, often achieving such liberatory status via communication technologies. Internet communities are an example of this. Members of contemporary communities are typically very heterogeneous, and they usually satisfy only one need through their involvement with a particular community. Contemporary individuals also interact in many different communities simultaneously, ending and reconstituting new relationships repeatedly. Commitment is rare as their purpose is nearly always time-limited and issue-specific. Finally, since diverse individuals join

49

communities to achieve personal gains, contemporary communities can be selfish and competitive sites where contradictions abound.

We may ask, to what extent are the features of what we here call traditional and contemporary community actually evident in communities, either in the present day North or South, or in communities of an earlier historical period? While the answer to this question lies beyond the scope of this thesis research, it is crucial to discern the extent to which communities *claim or are assumed to possess* these traditional features. This research argues that communities of the past and communities in the South are described and understood in very specific ways, irrespective of whether they ever existed in this form. Rightly or wrongly, this research contends, both IL and CBR assert a form of community imbued with traditional features, causing innumerable difficulties with respect to the implementation of community based disability initiatives. While not all features of either a traditional form or a contemporary form of community need be present in order to label it accordingly, these features provide a useful way of distinguishing between two quite different kinds of community. The Comparative Features of Traditional and Contemporary Community are presented in Figure 2.

This first half of Chapter 2 has examined in some detail the concept of community. The argument advanced is that selective features are attached, both unknowingly and knowingly, to communities. The second half of this Chapter will focus on the meaning of disability and the emergence of IL and CBR as two responses to disability. This review prepares the ground for a systematic investigation of the idea of community in IL and CBR.

50

## TRADITIONAL COMMUNITY

- Geographical
- Direct, Face-to Face Relations
- Members are Well-Known
- Homogenous
- Longterm
- Adhere to Tradition
- Loyal
- Committed to the Group
- Responsibility
- Protection of Communal Values
- Warmth, Caring
- Stable, Predictable

## CONTEMPORARY COMMUNITY

- Spatial and Temporal
- In-Direct Relations
- Members are Strangers
- Heterogeneous
- Time-limited
- Purposeful, Strategic
- Industrious
- Collaborate with Strangers
- Rights
- Attain Individual Gains
- Selfish
- Competitive, Contradictory

Figure 2    Comparitive Features of Traditional and Contemporary Community

51

**The Meaning of Disability**

There have been many attempts to define disability as an observable, measurable and meaningful construct. These efforts notwithstanding, a comprehensive understanding of the concept remains elusive for historical, ideological and cultural reasons. This section identifies the most salient features of disability, and describes the historical development of thinking about disability and its remediation.

<u>Working Definitions</u>

Any discussion of disability is problematic without first operationalizing a definition. The WHO classification system of impairment, disability and handicap is proposed (UN, 1983; Verbrugge & Jette, 1994; Wood, 1989), acknowledging that considerable controversy exists regarding the legitimacy of this system (Batavia, 1993; Hahn, 1985 & 1988; Oliver, 1984 & 1990; Wendell, 1989).

In the WHO schema, impairment refers to any loss or abnormality of bodily structure or function. Disability is any restriction or lack (resulting from impairment) of ability to perform an activity in the manner considered normal. Handicap refers to a disadvantage for a given individual (resulting from impairment or disability) that limits or prevents the fulfilment of normal social roles (UN, 1983, p. 3). The following example clarifies the distinctions: A blind (impaired) person may have difficulty writing a letter (disability). If, as a result, he is regarded as incompetent, then he is considered handicapped. (see Figure 3) These working definitions guide the remainder of the thesis research.

52

**DISEASE**          (intrinsic pathology or disorder)

↓

**IMPAIRMENT**       (loss or abnormality of psychological,
                     physiological, or anatomical structure
↓                    or function at organ level)

**DISABILITY**       (restriction or lack of ability to
                     perform an activity in normal manner)
↓

**HANDICAP**         (disadvantage due to impairment or
                     disability that limits or prevents
                     fulfillment of a normal role (depends
                     on age, sex, sociocultural factors) for
                     the person)

Figure 3    Impairment, Disability and Handicap
            (Adapted from Verbrugge & Jette, 1994)

53

<u>Disabled as Other</u>

Throughout history, disabled people have stood in stark contrast to society's

idealized images of human perfection (Barnes, 1996; Stone, 1995). Perfectly shaped

powerful young bodies are society's ideal. With respect to the disabled, however,

images of darkness and superstition abound. Visible physical disorders in particular

produce feelings of fear and awe. Eberly (1988) writes,

> Children born with major physical abnormalities have evoked a religious
> response since as least as early as 2000 B.C., when some 62 birth defects,
> whose appearance among Assyrian newborns was painstakingly examined and
> interpreted by professional soothsayers, were described in clay tablets found in
> the library of Nineveh. (Eberly, 1988, p. 58)

Warkany, in Eberly (1988) continues,

> In Rome, hermaphroditic children were summarily dispatched; other children
> with visible defects were particularly valued for sacrifice in time of emergency.
> Indeed, the old term for children born with marked deformities was *monster*, a
> word derived from the Latin *monstrum*, something marvellous, originally a
> divine portent or warning.... (p. 58)

This belief in the supernatural nature of the child born with a congenital defect

continued through the Middle Ages and into the Reformation. Kanner (in Eberly,

1988) reports that Martin Luther himself "labelled one severely retarded child as no

more than *massa carnis*, a soulless mass of flesh, and went so far as to recommend that

the child be disposed of by drowning" (p. 60). Disabled people were thought to be evil

omens, curses from God, and reincarnations of the animal and spirit worlds (Eberly,

1988; Miles, 1995). Eberly (1988), in her examination of disability folklore,

convincingly argues that many beliefs about the supernatural, changelings and fairies in fact describe congenitally deformed infants and children whose conditions today would be given a medical explanation. Where alternative explanations are lacking however, traditional (and usually erroneous) beliefs are often maintained.

In film and popular literature too, people with disabilities have been characterized as Other for centuries. People with disabilities have historically been a source of shame and embarrassment to their families and themselves. Zola (1986 & 1982) and others (Bogdan, Biklen, Shapiro & Spelkoman, 1982; Phillips, 1990) have sketched this history from Frankenstein's monsters, the Hunchback of Notre Dame, Dicken's Christmas Carol, and the evil witch in Snow White, to more contemporary disabling images like those in the movies Mask, Elephant Man and Chariots of Fire. Disabled people have been depicted as not only frighteningly disfigured, they are reduced to what Phillips (1990) calls damaged goods. Henry Enns, Executive Director of Disabled People's International (DPI) states,

> Commonly held myths are that handicapped people are psychologically maladjusted, that they are "sick," feeble-minded, in need of sheltering and protection and are asexual.... We see the disability, the white cane, crutches, hearing aid and wheelchair, but not the person. (Enns, 1982, p. 1)

Another powerful force in shaping the meaning of disability is language (Anspach, 1979; D'Aubin, 1991; Susman, 1994; Wang, 1992). Everywhere we read people *suffer* from arthritis or are *afflicted* with leprosy. They are *confined* to wheelchairs. And they are the *victims* of landmines and AIDS.

## Disability in the South

With the notable exception of the ethnographic work of Scheer and Groce (1988) and Groce and Zola (1993), there is strong evidence to suggest that in many parts of the South in particular, people with disabilities are characterized as defectives (Miles, 1995). Most often, the experience of disability is reduced to one of two stereotypical depictions: people with disabilities are portrayed as pitiful and neglected, or, they are believed, particularly the mentally disabled, to possess special powers that elevate their status to that of shaman or special elder. While both scenarios do occur, their prevalence is far less common than widely thought. Recent archaeological expeditions have unearthed skeletal evidence calling Inuit infanticide practices into question, for example (Scheer & Groce, 1988). Newcomer and Bard (in Enns, 1982) have also recorded numerous instances during the Ice Age where people with severely broken limbs, amputations and blindness were cared for by the members of their social groups. A more accurate portrayal of the treatment of the disabled in ancient societies may be that disabled persons participated quite broadly in their villages, tribes and clans, and for the most part, those societies were more accommodating of this one aspect of human diversity than previously imagined.

There is a tremendous spectrum of variation in the South as far as the cultural characterization of disability is concerned (Devlieger, 1995; Talle, 1995). While more research is required to inform this issue, culture dependent meanings of disability are our first concern. Some mild and moderate forms of disabilities and certain specific types of disabilities may not be identified as such in certain Southern countries (Groce

56

& Zola, 1993). For example, mild Parkinson's disease, a mild limb deformity, and a learning disability, might not be detected either by mothers or rural medical services. In addition, the label disabled may not be attached because the person functions in all meaningful ways without difficulty. Reciprocally however, within some cultures, traditional beliefs about the causes of certain disabilities tend to increase the stigmatization of such individuals. For example, if a child with cerebral palsy is thought to be possessed by evil spirits, then reactions and treatment of that child will be more negative than if the cause is understood to be a traumatic birth (Lysack, 1992). For disability to be understood, therefore, the historical and sociocultural context must be similarly understood. Woodward (1985) describes how Indonesians, for example, still adhere to many traditional attitudes about disability, including strong beliefs about the role of spirits and the supernatural. In rural areas especially, where levels of education are much lower, disability is typically described as "God's will -- a punishment for sins in a former life" (Deschesnes, 1995, March). Various myths about the origins of disability also abound. For example, and during previous research in Indonesia, Lysack (1992) observed a medical doctor on his bicycle swerve to avoid a snake, crashing and injuring his leg. In discussions afterwards, he conceded his behaviour was "probably irrational," but "he didn't want to take any chances" during his wife's first trimester. As a partial consequence of these superstitions, many rural Indonesian villagers think "people with disabilities have to accept it because nothing can be done" (Deschesnes, 1995, March). Many too are ashamed of disabled family members, refusing to allow them to participant in village events and organized

57

rehabilitation activities (Lysack, 1993). While there is significant variation in reactions to disability in the North and in the South, it can still be said that disability is viewed as an unfortunate occurrence, one which would be reversed, if it were possible.

## The Response to Disability

Historically, people with quite different disabilities have nearly always been grouped into a single inferior class (Nibert, 1995; Silvers, 1995). Since, being disabled meant being unable to work, disabled people were reduced to objects of social concern. This concern was first expressed through religious charity on the part of the superior class, and was much envied by other downtrodden groups such as the able-bodied poor who were denied such charity. Greenwood (1985) details the passage of the Poor Laws in Britain and how growing concerns about the expense of social aid, resulted in harsh treatment for the able-bodied poor. The "undeserving, wilfully malfunctioning poor" as Silvers (1995, p. 44) says, were condemned to work in punitive workhouses (Scull, 1990). The distinction between these groups was not that sophisticated however. Lumped together with the so-called unwilling paupers were some physically and mentally disabled people. Michel Foucault traces the genealogy of the institutions established to care for the poor and disabled in such classics as *Madness and Civilization* (1965). The conditions in the asylums were indecent, and treatment was less than human by today's standards. By the late 1800s however, there was a growing feeling of humanitarianism and the poor at least were accorded full rights as citizens. An increasing recognition of different disease etiologies also led to the

separation and treatment of the "misfits and defectives" from the "unwilling poor," and slowly more humane practices emerged. Silvers (1995) summarizes the subservient social position the poor and disabled found themselves in 100 years ago, that in some respects, is still present today:

> In view of their definitively deficient state, the deserving poor are not conceivably capable of themselves of the responsible use of whatever means charity bestowed on them. So another social group emerges: care-givers, persons whose profession it became to channel charity by administering it properly to damaged individuals. Thus, as a social class, the disabled became required by definition to be non-productive. They also became the means of production for members of another group, professional care-givers. (p. 44)

The most dramatic change in the evolution in the status of disabled persons came in the first half of this century in the aftermath of World Wars I and II. The advent of new medicines and the returning injured soldiers triggered the early development of rehabilitation as a profession, with services mandated by the state and delivered by a cadre of newly trained rehabilitation experts. Rehabilitation programs were developed throughout Europe and North America and rehabilitation specialties emerged shortly after this time (Bowe,1978; Gritzer & Arluke, 1985). While charitable relief continued for children and the aged, new social welfare systems and insurance programs emerged that began compensating people for industrial accidents and fatal illnesses. This was a major turning point in that disability benefits were not apportioned solely on the basis of charity. For those deemed permanently incapacitated, the key principle became compensation (Greenwood, 1985). However, in order to compensate the disabled, the fundamental problem of who counted as

59

disabled needed to be addressed. This task fell to the profession of medicine.

## Professional Rehabilitation

The World Wars spurred the development of many new drugs, the most important class of which was antibiotics. Through the combined power of medicine and science, it appeared that many chronic battles against disease would be won (Conrad & Schneider, 1980). In real terms, lives were saved, and serious illnesses were prevented, even cured. Under the medical model, treatment for the disabled became less punitive and there was less blaming of individuals for the moral deficiencies thought to cause their disabilities. There was a downside, however. Disabled people became, by definition, deviance from the norm, with pathologies residing in their sick bodies. Rehabilitation became the medically sanctioned path to cure (Bowe, 1978; Crawford, 1994; Navarro, 1974). Through compliance with expert guidance, prescribed regimes and specialized technologies, the deficient body systems were rectified and disease was overcome. In his now classic contribution to the sociology of illness, Parsons (1951) defined the social processes that in time came to be called the medicalization and professionalization of disability.

The power of this legacy has been described by several of its critics (Coburn, Torrance & Kaufert, 1983; McKinlay, 1977). Williams (1991) says the medicalization of disability represented a "dilation of the medical gaze," accomplished in such a way that "therapeutic failure can be blamed on forces outside the domain of medicine itself: the noncompliant patient or the obtrusive environment" (p. 520). In that way, medicine

60

could retain its professional power. In a finer enumeration of the process of medicalization, Zola (1991) contends that by retaining absolute control over key technical procedures and control over the label illness, medicine was inappropriately expanded to wider and wider arenas of life. "By the latter half of the twentieth century medicine had become so powerful a force in society that it was joining, if not nudging aside, religion and law as a major institution of social control -- in other words, as an arbiter of what was good, important, valuable in life" (Zola, 1991, p. 301).

## Primary Health Care

By the end of World War II it was apparent that efforts to meet the health needs of Southern countries through conventional Western technical services and national health structures "would require financial and personnel resources far beyond the capacities of the countries concerned" (Foster, 1982, p. 183). Innovative low cost approaches, socially and culturally appropriate to these countries, had to be developed. Primary health care (PHC) was the strategy designed to cope with the basic health needs of Southern countries, set in the context of integrated socioeconomic development.

As with community development more broadly, PHC has deep roots, and early attempts to meet basic community health needs can be found in most Southern countries as early as the 1940s (Christenson & Robinson, 1989). The term itself however, and operational definitions, took a further 20 years to appear.

The first study to describe and analyze successful attempts to adapt health care

61

to the needs and resources of Southern countries was commissioned by a WHO-UNICEF Joint Committee on Health Policy in 1971. By 1975, the 28th World Health Assembly formally approved the policy in an official resolution. Later that year, as Foster (1982) reports, the WHO's Director-General responded to this resolution with Promotion of National Health Services Relating to Primary Health Care. This statement was further elaborated at the Declaration of Health for All Conference held in the former USSR in 1978. At Alma-Ata, PHC was defined as "essential health care made universally accessible to individuals and families in the community by means acceptable to them, through their full participation and at a cost that the community and country can afford" (WHO, 1978, p. 34). Other essential elements of PHC include the use of effective traditional healing practices; recognition of community felt-needs as the basis of PHC activities; recruitment and training of PHC workers selected with the participation of the community; the use of locally available and sustainable materials and funds; and finally, an intersectoral government approach at all levels (WHO, 1975). Important as the development and provision of basic services was, Foster (1982) adds that "the development of local initiative, individual and community reliance, self-confidence, and a cooperative spirit" (p. 187) were also essential and were stressed as well. Thus, PHC had a significant social dimension. The basic philosophy of PHC was that "working on those problems which the community perceives as its own priorities will lead to community satisfaction and confidence in its own achievements" (WHO, 1975, p. 115).

The field of medical rehabilitation was attracted to PHC's pragmatic approach

and its commitment to the ideal of community participation (Finkenflügel, 1993).
Wishing to integrate disability into existing PHC networks in the South, efforts were
made to enhance the quality of life for persons with disability through medical
rehabilitation delivered to the villages where disabled persons lived. That approach
came to be called CBR.

## Community Based Rehabilitation

The concept of CBR is generally believed to have originated in tandem with
PHC in the 1970s as rehabilitation was recognized as an essential part of the movement
toward community participation in health (WHO, 1981 & 1982). Like PHC, CBR as a
local grassroots initiative was initially investigated for its viability in bridging the gap
between the increasing "burden" of disability in the South and scarce professional and
financial resources. After some preliminary success in smaller projects, CBR was
formally endorsed by the WHO in 1978, and large-scale demonstration projects were
established in Africa, India and Asia (UN, 1986). Special CBR publications such as
WHO's Training in the Community for People with Disabilities were also
commissioned and disseminated broadly (Chermak, 1990; Helander, Mendis, Nelson
& Goerdt, 1989; WHO, 1982). As McColl and Paterson (1995, September) note, the
UN further promoted the ideal of greater participation by disabled people themselves by
proclaiming 1983 to 1992 the International Decade of Disabled Persons, and afforded
the notion of CBR global recognition in its report entitled the World Programme of
Action Concerning Disabled People (UN, 1983 & 1986).

The models of CBR are many and vary widely (Helander, Mendis, Nelson & Goerdt, 1989; Kisanji, 1995; Miles, 1993; Peat, 1991b). While large rehabilitation centres exist in the South, they are virtually always located in cities, completely inaccessible to the majority of people with disabilities. In Indonesia, for example, it is estimated that only 5% of disabled people have access to the urban centres (Johnston & Tjandrakusuma, 1982). O'Toole (1987) estimates that in Southern countries generally, rehabilitation centres treat at most 1-2% of people with disabilities. As a result, CBR has continued to expand ever since the late 1970s.

CBR today is promoted by many organizations, governmental and NGO alike. CBR is viewed as a way of building upon the resources of disabled people, their families and communities, and extending services in an affordable and culturally sensitive manner to a large proportion of otherwise under served and often rural disabled people (Peat, 1991a & 1991b). CBR projects are often planned as national programs under the auspices of a country's health ministry, as in the case of India and Vietnam, for example. Some projects are heavily influenced by the WHO's model of CBR, for example, Botswana, the Philippines, Nigeria and Burma (WHO, 1982). In some other countries, they are developed as individual projects targeting a single village. This is more often the case when the CBR project is supported by a smaller, likely private NGO. Projects may include the services of medical professionals, but this is not a necessity. Increasingly, many CBR projects focus on vocational training and income-generation -- one of the highest priorities of disabled people themselves. CBR is also usually closely affiliated with PHC and the social welfare system. In this

way CBR acts as a bridge between the community and institutionalized services (WHO, 1981 & 1982). In all such projects however, CBR's primary aim remains the same: raising awareness about disability, promoting positive attitudes toward people with disabilities, early detection of disability problems, and provision of simple equipment and interventions (ILO/UNESCO/WHO, 1994). The ultimate goal is improving the everyday lives of disabled people, not only through medical rehabilitation, but also through social inclusion and political equality.

Two definitions of CBR illustrate the range of ideas encompassed by the CBR philosophy. The first definition reflects a Western orientation. In 1994, after one year of extensive consultations, the International Labour Organization (ILO), United Nations Educational Scientific and Cultural Organization (UNESCO), and WHO jointly issued their consensual international definition. They defined CBR as follows:

> A strategy within community development for the rehabilitation, equalization of opportunities and social integration of people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, educational and social services. (p. 2)

The second definition reflects a Southern NGO perspective. This definition guides CBR implementation at the YPAC (Yayasan Pembinaan Anak Cacat, or the Indonesian Society for the Care of Disabled Children) CBR Center in Indonesia which has been training CBR workers in rural Indonesian villages for more than 30 years (Sutopo, 1993).

CBR involves efforts to change the community's perception and behaviour (including attitudes, knowledge and skills), so that community members are able to realize the various problems the disabled face (that is, socioeconomic, sociocultural, medical, psychological problems) and are able to provide the disabled with a good atmosphere in which they can solve their problems and in the end improve their quality of life. (p. 7)

## The Disability Movement

Professional rehabilitation as the appropriate response to disability created a

number of serious problems from the perspective of people with disabilities and has

been attacked on several fronts (Albrecht, 1992; Friedson, 1970a & 1970b; Gritzer &

Arluke, 1985). One of the major difficulties relates to the presumed dichotomy

between the normal and disabled under the medical model. When can it be said that

within the broad continuum of human variation normalcy ends and disability begins?

Disability may have a contextual component. After all, what is considered a normal

role for one's age, sex, and culture? Do standards of normalcy not depend upon the

society within which they are generated? (Wendell, 1989) Much about what is

disabling about one's physical condition is also a consequence of social arrangements.

Researchers in the area of menopause for example, have compellingly argued that such

human processes are socially constructed from biological reality (Kaufert & Gilbert,

1986). The boundaries drawn between the social and the biological may be quite

artificial and a universal biological definition of disability may be an illusion.

A second major difficulty is that the label disabled applied by medical

definitions may not fit the people to whom it is attached. Thus some people are

66

perceived as disabled who do not experience themselves as disabled. On the other hand, some people whose bodies cause them great physical, psychological and economic struggles are not considered disabled because the public, and especially the medical profession, do not recognize and officially sanction their disabling conditions.

From the perspective of people with disabilities too, the medicalization and professionalization of disability is objectionable on many grounds. First, they argue, the doctor-patient relationship of domination reinforces notions of sickness and dependence (McKinlay, 1977; Zola, 1986 & 1993). Further, it impedes the goals of autonomy and self-determination, the benchmark of the disabled consumers movement (Boschen & Krane, 1992; Jongbloed & Crichton, 1990). One of the disability movement's first targets, then, was the medical profession and their control over the definition of disability. They opposed the medical definition of disability because it implied deficit (Valentine & Vickers, 1997). Moreover, they challenged the notion that disability resided in their bodies, and rejected the argument that medical science provided the cure. Instead, disabled consumers advanced the IL model, a model where the personal experience of disability was not discounted, a model where disabled people were encouraged, not discouraged, to seize control of their own lives (Schlaff, 1993; Sutherland, 1981; Zola, 1982; Williams, 1983). The IL philosophy meant that disabling attitudes and environmental barriers were society's problem; accordingly, society became responsible for a more positive response.

## Independent Living

During the 1970s and early 1980s there were indications a new social movement of people with disabilities was developing around the world (Driedger, 1989). In many respects, the movement was dramatically fuelled by a growing consumer mentality, the 1960s civil rights ideology, and the impact of returning Vietnam War veterans in the United States (DeJong, 1979; Morris, 1991; Scotch, 1988 & 1989). As in so many other areas of Canadian life, ideas about disability activism spilled over the border from the United States several years later. Enns (1982) and Valentine (1994) trace the early struggle for disabled people's independence in Canada and detail the distinctions between Canadian and American versions of the movement. For all activists, however, the new movement congealed when the concept of consumerism was integrated into a movement of people who, sensing power in their shared experience, united to resist what they viewed as societal and medical oppression. Influenced by the IL ideology, disability advocates thereafter have claimed that: (1) disabled people are not sick, and that (2) no one knows better what disabled people need than they themselves (Derksen, 1980). This new way of thinking contributed to the idea that disabled persons were far more like an oppressed minority than sick patients (Oliver, 1984 & 1990). This fundamental shift in the idea of disability, from a medical to a sociopolitical notion, meant that neither charity, medical care, nor financial compensation would characterize future disability policy. Disability was not personal tragedy and disabled people were not victims. The new watchword was political inclusion (Batavia, 1993), and the new principle guiding society with respect to disability became equal opportunity (Derksen,

68

1980).

Most basically, the IL philosophy asks that people with disabilities be
recognized and treated as equals. Two definitions of IL illustrate the range of ideas
encompassed by the term IL. The first definition, reflecting a Western orientation, is
provided by DPI, the world's largest international cross-disability organization of
people with disabilities.

> IL is a process of consciousness raising and empowerment. This process
> enables disabled people of all ages and with all types of disabilities to achieve
> equalization of opportunities and full participation in all aspects of society.
> Disabled people must be in control of this process. Meaningful choices must be
> available in order to exercise control. (DPI, 1995)

The second definition is currently the accepted definition of IL in Indonesia and first
appeared in the Manual of Self-Help Organizations of Disabled Persons published by
the Economic and Social Commission for Asia and the Pacific at the UN in 1991. This
definition was adopted at the Asia-Pacific Regional Conference of Rehabilitation
International (RI) in 1995, the same Conference that proclaimed open the Asia-Pacific
Decade of the Disabled.

> Independent living means living just like everyone else -- having opportunities
> to make decisions that affect one's life, being able to pursue activities of one's
> own choosing -- limited only in the same ways that one's non-disabled
> neighbours are limited. Independent living should not be defined in terms of
> living on one's own. Independent living has to do with self-determination. It is
> having the right and the opportunity to pursue a course of action. And, it is
> having the freedom to fail -- and to learn from one's failures -- just as non-
> disabled people do.

Just as the medicalization of disability wrought problems for disabled people, so too has the adoption of primarily a sociopolitical definition of disability. One significant problem has been the applicability of this approach to the South. For example, are individual rights and advocacy a priority in contexts where protection of the less fortunate is a dominant cultural value and where basic health needs have yet to be addressed? Furthermore, Western liberal notions of self-determination and autonomy may not always be appropriate in Southern contexts. Although the community and family are frequently identified as untapped resources for sick and disabled persons, the affectionate desire to help and protect disabled people has the potential to maintain them in a state of dependency. While the rights and independence of people with disabilities are still issues of central importance to the disability movement in the North, it remains unclear how the IL ideology can successful transfer these founding principles to the South.

## Summary

The first part of this chapter described the widespread use of community language in international health. The section that followed provided important background about the sociological origins of the idea of community and its contemporary meaning. In that section, a distinction was drawn between the ideas of traditional and contemporary community and it was argued that through a process of abstraction, traditional features can be applied to communities of various kinds. The third section of this chapter reviewed the evolution in the meaning of disability and

70

explored the characterization of people with disabilities as Other and unfortunate victims of fate. While there has been an evolution in their treatment from charitable care to professional treatment, for the most part, this group has been excluded from mainstream society. The final section of the chapter described IL and CBR, two alternate approaches to disability. While both favour the redress of disability problems in the community, CBR, originating as it did from professional rehabilitation, views the solution in terms of provision of basic services to under served populations. IL, representing as it does a social movement of disabled people, remains committed to a human rights agenda.

The thesis research aims to critically investigate the po·ver of the concept of community within the international disability discourse. With a review of the concepts of community and disability and the approaches of IL and CBR now complete, we can turn to an explication of method.

71

# STUDY DESIGN, METHODS AND ANALYSIS

## The Research Design

Studying the idea of community and its function within the context of IL and CBR requires an historical and reflexive theoretical approach. Such an approach, as argued in the introductory chapter, must preserve the contextual understanding of social constructivism, and combine it with the normative foundation of critical theory and the scepticism of postmodernism. I called this hybrid critical postmodernism and adopted it as the guiding frame for the research.

Methodologically however, the research has several further requirements. For example, its comparative aspect demands a research design that is flexible and responsive to unanticipated occurrences of significance. The design must also follow logically from the research goal as well as the pragmatics of the situation (Smaling, 1994). The occasions for data collection in this research were varied and included field visits in Canada and Indonesia, review of official international health policy and specific IL and CBR program documents, as well as interviews with key IL and CBR leaders. Since the primary aim of the research was understanding the importance of the idea of community in this complex comparative context, a case study design was selected for the research.

72

<u>The Logic of a Comparative Case Study</u>

The thesis research was originally formulated as two conventional case studies focussed on the implementation of IL and CBR programs. As the awareness of the centrality of the idea of community in the assertions of IL and CBR developed however, the research evolved into an analysis of IL and CBR as ideologies and the goal of the research became an effort to reveal the function of the idea of community within them. (see Figure 4) Although demanding, a study lacking this scope would be inadequate in several ways. Only an international comparison encourages scrutiny of the impact of IL and CBR ideologies, developed as they are in the West, on disability programs delivered in the South, for example. There may also be trends in the use of language in the conceptualization of disability. Since detecting, tracing and explaining the variations in the language and meaning of community are a central concern of this research, the comparative framework was essential.

**Research Settings**

Data were gathered in four geographical locations, two in Canada (the North) and two in Indonesia (the South). For simplicity, they are designated: CBR North, IL North, CBR South, IL South.

Like the focus of the research, the research settings evolved from the original proposal. As the research broadened to encompass the idea of community and its function within IL and CBR ideology, the definition of the research sites also expanded, more properly becoming research settings rather than conventional field sites. While

73

the North-South dimension of the original research was preserved, the importance of specific organizational sites diminished as the importance of settings where useful ideological data could be obtained increased. Figure 5 presents the Research Setting, Location and Organizations. Figure 6 identifies the Key Data Events and Opportunities in the four research settings. The organizational participants are identified and described shortly.

## The Canadian Setting

The Canadian (North) research setting was twofold: Winnipeg, Manitoba and Kingston, Ontario. These settings provided data about IL in the North, and CBR in the North, respectively.

CBR North was the International Centre for the Advancement of Community Based Rehabilitation (ICACBR). ICACBR was established in May 1991 in Kingston, Ontario as one of six Centres of Excellence funded by the Canadian International Development Agency (CIDA). The Centres of Excellence program was established to "encourage and support bold and imaginative teaching, training, research and public awareness related to international development" (ICACBR, 1993, January, p. 2). CIDA was the principal funder of ICACBR, providing $5.5 million in support over a six year period. Affiliated with the School of Rehabilitation at Queen's University and more than 25 individuals representing 11 partner agencies in Bangladesh, Canada, India, Indonesia and internationally, ICACBR is the location of greatest CBR research and program development in Canada. Four Standing Committees are currently in

74

**Comparison of
Program Delivery**

**Impact of Ideology
on Programs**

**Function of Idea
of Community in
Ideology**
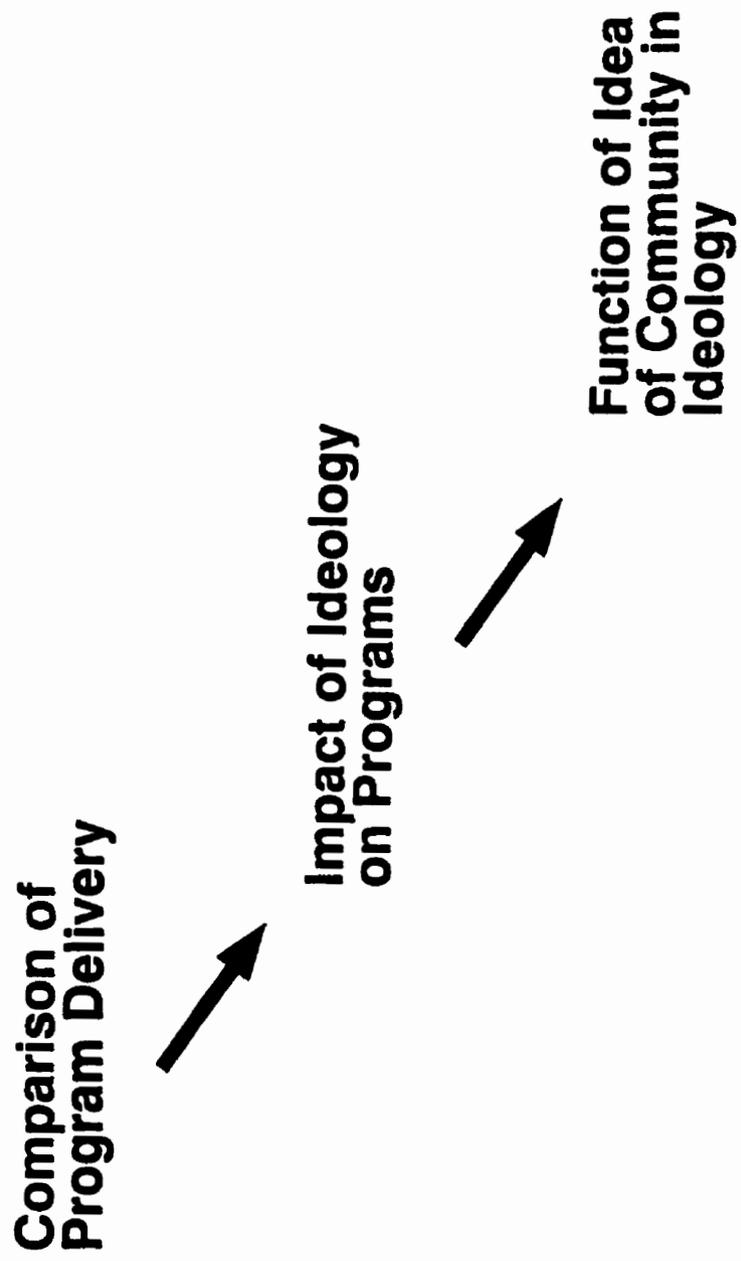
Figure 4    Evolution of the Scope of the Research

| SETTING | LOCATION | ORGANIZATIONS |
|---------|----------|---------------|
| CBR NORTH | Kingston, ON | ICACBR |
| IL NORTH | Winnipeg, MB | DPI & CCD |
| CBR SOUTH | Solo, Indonesia | YPAC Prof. Dr. Soeharso CBR Center |
| IL SOUTH | Jakarta, Indonesia | 10th Annual Asia-Pacific Conference of Rehabilitation International |

Figure 5    Research Setting, Location and Organizations

## CBR AND IL NORTH

Asia in the 90s: Meeting and Making a New World, An International Conference on Asia sponsored by Studies in National International Development and ICACBR, in Kingston, October 1993.

Progress Through Partnerships, The National Independent Living Conference, in Winnipeg, August 1994.

Health Reform Around the Globe: Towards Equity and Sustainability? The Second Annual Canadian Conference on International Health, in Ottawa, November 1994.

## CBR AND IL SOUTH

Reaching the Unreached, The 10th Annual Conference of the Asia-Pacific Region of Rehabilitation International, in Jakarta, Indonesia, October 1995.

Asia and Pacific Adaptations of Independent Living and Community Based Rehabitation, IDEAS Workshop on IL and CBR, held in conjunction with the RI Conference in Jakarta.

The Future of CBR - Crucial Issues, a Pre-Conference Workshop on CBR, held in conjunction with the RI Conference in Jakarta, at the YPAC CBR Center in Solo.

Evaluating Community Participation, Workshop sponsored by ICACBR and Queen's University, in Kingston, October 1996.

Figure 6    Key Data Events and Opportunities

place at ICACBR: Demonstration Projects, Evaluation, Learning Fora, and Research. Representatives from partner organizations enable ICACBR "to enrich our own CBR experiences, while adding to the body of knowledge about the theory and practice of CBR" (ICACBR, 1993, January, p. 3). ICACBR was thus the primary source of academic and policy related CBR data and the main source of CBR program evaluation reports. As a result of continuing collegial relationships between the researcher and several scholars at ICACBR, informal opportunities to discuss CBR and IL issues continued over the 3 1/2 year period of the dissertation research.

IL North, located in Winnipeg, consisted of two organizations: DPI and the Council of Canadians with Disabilities (CCD). Winnipeg is the site of several major disability organizations. The history of the disability movement is therefore influenced by this geographical concentration o⁺ key individuals and local historical events. As Enns (1982) and also Valentine (1994) report in some detail, the Coalition of Provincial Organizations of the Handicapped, eventually renamed CCD, was founded in Winnipeg in 1976. This national cross-disability umbrella organization has claimed to be the voice of all disabled Canadians since its inception. Today CCD represents more than 1300 consumer controlled disability groups. CCD is not a direct service provider however. Its primary mission is the formulation of disability policy and collective social advocacy.

Winnipeg's prominence on the international disability stage was established when the UN proclaimed 1981 the International Year of Disabled People, and exceptional disabled Canadians like James Derksen, Allan Simpson and Henry Enns

78

began to lobby the federal government to provide accessible services, like transportation for example, to disabled people just as they did for all other citizens (Driedger, 1989). Once again, the historical narrative of the movement was defined by local disability advocates. One year prior to the staging of this worldwide event the World Congress of RI convened in Winnipeg. Driedger (1989) details how tensions between people with disabilities and rehabilitation professionals at the Congress erupted over the issue of representation in the RI Assembly. The collective energy generated by the charisma of prominent Winnipeg activists, coupled with the masterful orchestration of the disabled delegates in attendance, resulted in the birth of a new international organization of disabled people, later to become known as DPI. DPI, with its international headquarters in Winnipeg, claims over 100 countries in its membership. It is the largest disabled consumer organization guided by the IL philosophy in the world. DPI and CCD are both actively involved with the disability movement in the South and financially support disability projects in numerous countries in Southeast Asia, Africa, the Caribbean, and South America. Ideological and programmatic data about the disability movement and IL philosophy were obtained at both DPI and CCD.

Secondary IL program data were collected from the Independent Living Resource Centre (ILRC) in Winnipeg. The ILRC is one of 21 consumer oriented self-help organizations in Canada. As the researcher served as a voluntary committee member for a fund raising initiative at the ILRC from September 1994 to September 1995, relevant information was occasionally presented to the researcher for "inclusion

79

in her study." Becoming aware of the more mundane and everyday workings of this disability organization contextualized the more formal data thereby providing a more complete understanding of the Canadian disability scene.

## The Indonesian Setting

The Indonesian (Southern) research setting consisted of Solo (CBR South) and Jakarta (IL South) respectively. CBR South was very familiar to the researcher as her Master's research was conducted there. Solo is situated in Central Java where Yayasan Pembinaan Anak Cacat (YPAC), the Indonesian Society for the Care of Disabled Children, has been involved in CBR activities for more than 30 years (ICACBR, 1993, September). Founded in Jakarta in 1953, YPAC today includes 16 centres for children with disabilities throughout Indonesia. In 1978, after realizing institutional rehabilitation services for rural children would likely remain extremely limited for the foreseeable future, YPAC and Dr. Handojo Tjandrakusuma began developing their ideas about community rehabilitation. In 1983, YPAC developed their first series of manuals for training village volunteers to detect disabilities and provide simple interventions. In 1986, realizing a separate organization within YPAC was necessary to focus on CBR exclusively, the Prof. Dr. Soeharso CBR Development and Training Center was established in Solo and Dr. Handojo was appointed Director.

The Solo CBR Center, completed in 1989, consists of office facilities, a library, conference hall, several smaller lecture rooms and a 22-room dormitory. The facility is used for training CBR cadres and for various CBR conferences and workshops. Center

staff work closely with the Indonesian Department of Health and Social Welfare. Presently, the Center's primary efforts are aimed at developing CBR programs in 8 districts in the province of Central Java, with the intention of extending CBR to the entire island. The CBR Center is a high-profile CBR organization in Southeast Asia with growing expertise in the development and distribution of educational materials for CBR. CBR Center activities are currently funded by the Dr. Ip Yee Charitable Trust in Hong Kong and the Sasakawa Foundation in Japan. In a fortunate turn of events viz a viz the thesis research, the CBR Center hosted an intensive week long Pre-Conference Workshop on CBR in September 1995 in conjunction with the 10th Annual Conference of the Asia-Pacific Region of RI. Entitled The Future of CBR -- Crucial Issues, this was a unique opportunity for 36 invited participants. including this researcher, to discuss the future of CBR internationally.

The final setting, IL South, was the Asia-Pacific RI Conference mentioned above with the conference theme, Reaching the Unreached. This timely event provided numerous interview opportunities. It also facilitated collection of unpublished, and notoriously difficult to obtain, archival materials from numerous DPOs active in IL and CBR in the South. A number of prominent European disability and rehabilitation spokespersons were also in attendance at the Conference, including representatives from the UN, ILO and WHO. The Solo Pre-Conference Workshop on CBR was another opportunity to interview disability leaders. In the South, the demarcation between IL and CBR is not as clear as in the North. Opportunities to collect CBR data often overlapped with those for IL data. In combination however, the research settings

81

and data collection opportunities permitted at least a preliminary glimpse into the internal operations of international IL and CBR. While geographically accessible and familiar to the researcher, they also represent logical choices. These organizations are the best known and most highly respected in the field of IL, and the meetings and conferences were unique opportunities to gather international perspectives on community based disability and rehabilitation efforts.

## Data and Collection Methods

The case study incorporates three major data collection methods in its design: key-informant interviews, review of archival documents, and field observation. Key-informant interviews are crucial data sources as they provide new data on the micro-histories of IL and CBR. Although some documentation of the histories and development of IL and CBR is available (Driedger, 1989; Helander, 1993), these resources are selective and often serve specific organizational and political purposes. Archival documents are also important data sources because they represent the primary means by which IL and CBR disseminate their ideology to people with disabilities and those supportive of community based initiatives more generally. Field observation was the final method of data collection in this study and proved essential in establishing the credibility of key-informant and archival data. Time in the field ensured that ideological policy, both spoken and written, were actually correlated with the reality of community based disability programs.

## Research Participants

ICACBR, DPI, CCD and the YPAC CBR Center were the primary organizational participants in the research. With their assistance, key-informants were identified and interviews were arranged. Thirty-eight interviews were conducted. A Profile of Key Informants is provided in Appendix A. Informants included directors and former directors of IL and CBR organizations, editors and contributors to international disability newsletters and journals, prominent disability researchers, IL and CBR project managers, and community based disability cadres and trainers of cadres. Approximately one-half of these individuals were disabled themselves. Informants interviewed for the thesis research reflect the researcher's network of international IL and CBR contacts. The sample of convenience is acknowledged. There are other important (albeit less accessible) individuals within IL and CBR whose views could not practically be captured in this study.

The key-informant interviews were deliberately qualitative and unstructured. The Guiding Interview Schedule is provided in Appendix B. The specific questions on the interview schedule also varied somewhat between IL and CBR participants. In general however, all were asked about their involvement and commitment to these movements and how they understood disability, community, empowerment, IL and CBR. Questions were posed about the providers and users of disability services and how deeply IL and CBR ideology permeated program activities and their respective constituencies. Finally, all informants were asked to comment on the impact of personal, organizational and political factors on the success of the community based

83

disability projects.

Ideological spokespersons for IL and CBR were asked to detail the ideological histories of these approaches and comment on their success within a broader societal context. They were also asked how effective they believed their specific programs were in addressing the stated needs of people with disabilities.

People with disabilities who participated in IL and CBR programs were similarly queried about the details of IL and CBR philosophy and how relevant and effective they felt these programs were. Individuals were also asked about their daily living situation and what kinds of disability assistance and services they found most helpful. Interview questions were open-ended and flexible so that unexpected and interesting turns in the discussion could be carefully pursued.

The majority of the 38 interviews were audiotaped and typically lasted 90 minutes, although five interviews were quite lengthy, lasting between 2 1/2 to nearly 4 hours. To avoid missing unscheduled spontaneously occurring interview opportunities, nine of the interviews relied upon fieldnotes only.

Textual Data

Key-informant interview data were evaluated within a framework influenced by international health and disability policy. Policy documents thus became a central textual source of data for the research. Official international materials such as the WHO's Alma-Ata Declaration on Health for All and the UN's World Programme of Action Concerning Disabled People were core documents. Since IL and CBR ideology

84

is also shaped by specific organizations and their respective missions, official position statements and other prominent documents from these organizations were central to the analysis as well. The official program mandates of these organizations were also important because they grounded the ideas of the ideology in concrete programmatic terms. These data added another dimension to the textual data already derived from the international policy context.

In addition to policy and program level data about IL and CBR, there is a small but growing academic literature on IL and CBR. As the research evolved into a study of language and ideology, it became apparent that all scholarly papers about IL and CBR were potentially crucial data sources for this research. Published manuscripts such as those by Peat (1991a & 1991b) for example, provided data about the development and structure of CBR. Evaluations of CBR projects, both published (Armstrong, 1993; Lagerkvist, 1992) and unpublished (Miles, 1985; Periquet, 1989; Sutopo, 1993) were also important sources of CBR data. The disability movement has produced somewhat fewer official documents, but they were nonetheless equally important. The proceedings of the World Congresses of DPI (DPI, 1982 & 1992), for example, were crucial sources of data. Reports about IL sponsored disability projects in the South are less likely to be published than those of their relatively better resourced CBR counterparts. Therefore, reliance upon a well-known network of IL and CBR informants was imperative for a balanced analysis. Miles' (1985) Where There is No Rehab Plan and Kugelmass's (1990) Indonesian System of Caring are examples of important sources on disability needs and social responses to disability in the South.

85

These documents were included as data in this research. Materials for training disability workers were also important sources for gaining insight into the differential emphasis of governments and NGOs with respect to disability projects. Poedjangga (1991, May) and Soepangadi (1986) provide examples of such materials. Finally, practical IL and CBR project information is most frequently communicated in international disability magazines and newsletters. The following publications were reviewed for this research: Vox Nostra, A Voice of Our Own, ActionAid Disability News, CBR News, CBR Update, CBR Frontline Digest, Disability in Action, and News on Health Care in Developing Countries. In summary, a plethora of policy documents, position papers, magazine articles, academic papers and historical treatises relating to IL and CBR were examined. Data distilled from these archival sources were integrated with interview and participant-observation data. All data became text for purposes of data analysis.

## Enhancing Data Trustworthiness

One of the critical issues in case study research is establishing the trustworthiness or quality of study findings. Lincoln and Guba (1985) describe strategies for addressing both validity and reliability concerns.

Perhaps the greatest concern rests with the study's overall credibility, sometimes called construct validity. Construct validity refers to the likelihood that the study has successfully captured the phenomena of interest. In other words, how can we be sure that the questions asked and the documents reviewed, for example, are really the ones

that must be studied in order to understand the topic? The question of whether other researchers would have reached similar conclusions rests, in large part, with the expertise and integrity of the researcher herself (Denzin, 1994; Punch, 1994). There are three ways to address the credibility concern.

The first technique is to return data gathered via indepth interviews to the original informants for checks on data completeness and precision. Lincoln and Guba (1985) call this technique member-checking. Due to time constraints in the Southern (Indonesian) research setting, this was not possible. The interviews were only transcribed after return to Canada. In the Northern setting (Winnipeg and Kingston), participants who wished to review interview transcripts, did so. This technique enhanced data accuracy.

Data accuracy is only one aspect of construct validity, however. Member-checking does not address the interpretation issue, that is, whether the researcher has properly understood and represented informants views on a given topic. The interpretation issue is addressed in this research by employing the constant comparative method in the tradition of Glaser and Strauss (1967). Throughout data collection, the researcher came into repeated contact with her key-informants. Thus, informally there were opportunities to clarify meanings and beliefs about disability, IL and CBR. There were also formal opportunities to do so, such as in the production of papers for publication. Three papers were undertaken in this spirit: a discussion paper on CBR prepared for a DPI Congress in Sydney, Australia (Lysack & Kaufert, 1994b), a magazine article for a Canadian disabled consumer audience (Lysack, 1996d), and

87

finally, an academic conference paper coauthored and presented with a disabled

consumer (Lysack, Martinez & Kaufert, 1996). In their preparation, these papers were

circulated for comment among IL and CBR spokespersons. This was an iterative

process where original transcript material, over time, was incorporated into a more

integrated analysis.

The second technique to enhance study credibility is to collect data over an

extended time frame so that study participants feel comfortable with the researcher and

vice versa. This technique is called prolonged engagement in the field (Lincoln &

Guba, 1985). Prolonged engagement in the field is advantageous in that it permits time

to check details and seek further clarification when confusing or particularly interesting

data emerges. The researcher's "insider status" was an advantage in this regard as

researcher and participants were already familiar with disability terms and practices

(Marshall & Rossman, 1989). During previous study, the researcher had come in

contact with several prominent disability scholars and also visited a high-profile CBR

project in Solo, Indonesia. Hence, it was unnecessary to devote large amounts of time

to become familiar with the current issues and concerns of international disability. The

data collection phase persisted over approximately 18 months. This provided more

time for relationships between researcher and participants to develop. The

strengthening relationship was evidenced by the increased amounts and kinds of

information gained in the second, third and fourth visits that were not revealed in

earlier contacts. For example, the earliest stages of data collection produced primarily

historical information about the development of IL and CBR and general program

information. Later data consisted of documents typically circulated internally to trusted members of IL and CBR organizations. Informal reciprocal commentaries about the past behaviours, positions and actions taken by representatives of Il and CBR ideology were also more frequent toward the end of data collection. As the literature supports, data that could be construed as somewhat negative in nature or that opposed popular consensus were more likely to emerge in later meetings than earlier ones (Silverman, Ricci & Gunter, 1990). Toward the end of data collection, IL and CBR informants would contact the researcher on their own accord when they perceived issues of interest to her were developing.

The third and final technique to enhance study credibility is popularly called methodological triangulation (Greene & McClintock, 1985). This technique requires that multiple informants be queried and multiple documents analyzed. Triangulation as a strategy implies utilization of multiple independent sources of evidence so that when convergence is obtained the researcher has greater assurance that the information is valid (Lincoln & Guba, 1985; Krefting, 1990; Ratcliffe & Gonzalez-del-Valle, 1988). Richardson (1994) claims however, that in our postmodern world "a rigid, fixed, two-dimensional object" (i.e., the triangle), should not be the central image for research validity. For Richardson, the preferable image is the crystal because of its complexity and multidimensionality. It is worthwhile to consider Richardson's viewpoint. In her words:

> The central image is the crystal, which combines symmetry and substance with an infinite variety of shapes, substances, transmutations, multidimensionalities,

and angles of approach. Crystals grow, change, alter, but are not amorphous. Crystals are prisms that reflect externalities and refract within themselves, creating different colors, patterns arrays, casting off in different directions. What we see depends upon our angle of repose. Not triangulation, crystallization.... Crystallization, without losing structure, deconstructs the traditional idea of "validity" (we feel how there is no single truth, we see how texts validate themselves); and crystallization provides us with a deepened, complex, thoroughly partial, understanding of the topic. Paradoxically, we know more and doubt what we know. (p. 522)

How does methodological crystallization pertain to this research? It means that the researcher take all points of view and all evidence as necessarily partial, fundamentally incomplete. Because no ultimate truth is possible, the best that can be done is to strive to fairly represent contending perspectives. To do so requires the use of multiple sources of data and multiple methods of data collection. In this study, observational opportunities associated with the research were purposefully incorporated into the overall study design. Observations were critical and sceptical, however, as critical postmodernism commits the researcher to the position that reality can be represented not only unconsciously, but also deliberately and strategically. All forms and sources of data must then be treated as discourse that requires deconstruction. No data can be accepted at face value. The researcher must be consciously reflexive throughout the data collection and analysis stages, well aware that all data is generated in a social context and most often is created for a social purpose as well. A search for counter-intuitive evidence is therefore also essential. Data collected in this way is then compared with data collected at meetings, from key-informant interviews and archival review. Self-report data are evaluated alongside observations of actual behaviours and

actions. The use of multiple sources and kinds of data was a deliberate strategy for overcoming the weaknesses and limitations of individual methods alone (Brewer & Hunter, 1989; Sechrest & Sidani, 1995; Yach, 1992). Although individual methods contain flaws, the flaws in each are not identical. The multimethod strategy thus provides a method with multiple but nonoverlapping weaknesses and a combination of complementary strengths. The primary benefit of the multimethods approach is the broad range of data it generates and the opportunities for comparison this diversity affords. All of these techniques were utilized in this research.

The second major concern for case study research is external validity, or the transferability of the findings. This test refers to the generalizability of study findings. For case studies, it is important to recognize that the crucial test is not whether the findings generalize to other cases, but whether study findings generalize to theory (Yin, 1994). Like the classical experiment, the case study relies on analytical, not statistical, generalization. As Krefting (1990) states, transferability is enhanced by providing a rich detailed case description -- a study recognized by knowledgeable others as a "shared experience." This recognition notwithstanding, the reader is still required to engage the researcher's interpretations. The case must be described in "sufficient descriptive narrative so that readers can vicariously experience these happenings, and draw their own conclusions" (Stake, 1994, p. 243). The overall worth of the study then, is judged by the reader herself.

The final test of trustworthiness is reliability or dependability. As Yin (1994) states, reliability refers to the likelihood that another researcher, employing the same

procedures and studying the same case, would draw similar conclusions. Fastidious attention to detail is the best guard against reliability problems. An experienced researcher who deploys a multimethod data collection strategy, extensively described above, is also at an advantage in this regard. All of the measures described were employed in this research. Of course, as with every study, the final interpretation of research findings remains the author's alone.

## The Fieldwork Schedule

Fieldwork commenced in the spring of 1995 and concluded in November 1996. (see Figure 7) While the overall data collection period lasted 18 months, there were specific time periods during which targeted data collection activities occurred. For example, 5 weeks were spent in Indonesia in September 1995 where collection of IL and CBR program data was the primary activity. Ideological CBR data were collected during two separate visits to Kingston, Ontario in June 1995 and October 1995, for a total of 6 weeks of intensive CBR data collection. While in Indonesia and Kingston, data collection focussed on interviews with prominent disability and CBR spokespersons, academics, program personnel and service recipients. In addition, all pertinent written documentation that could not be copied or removed from the sites was studied in the course of research activities in these locations. To maximize the efficiency of the time spent in the field, transcription of interview data and formal analysis of interview data and archival data were commenced only after the researcher's return to Winnipeg. Data collected from DPI and CCD were collected more gradually

92

KEY

Intensive

Moderate

Preliminary Case
Study Development

Theoretical
Integration

CBR
NORTH

IL
NORTH

CBR
SOUTH

IL
SOUTH

| May | June | July | Aug | Sept | Oct | Nov | Dec | Jan | Feb | Mar | Apr | May |

'96

'97
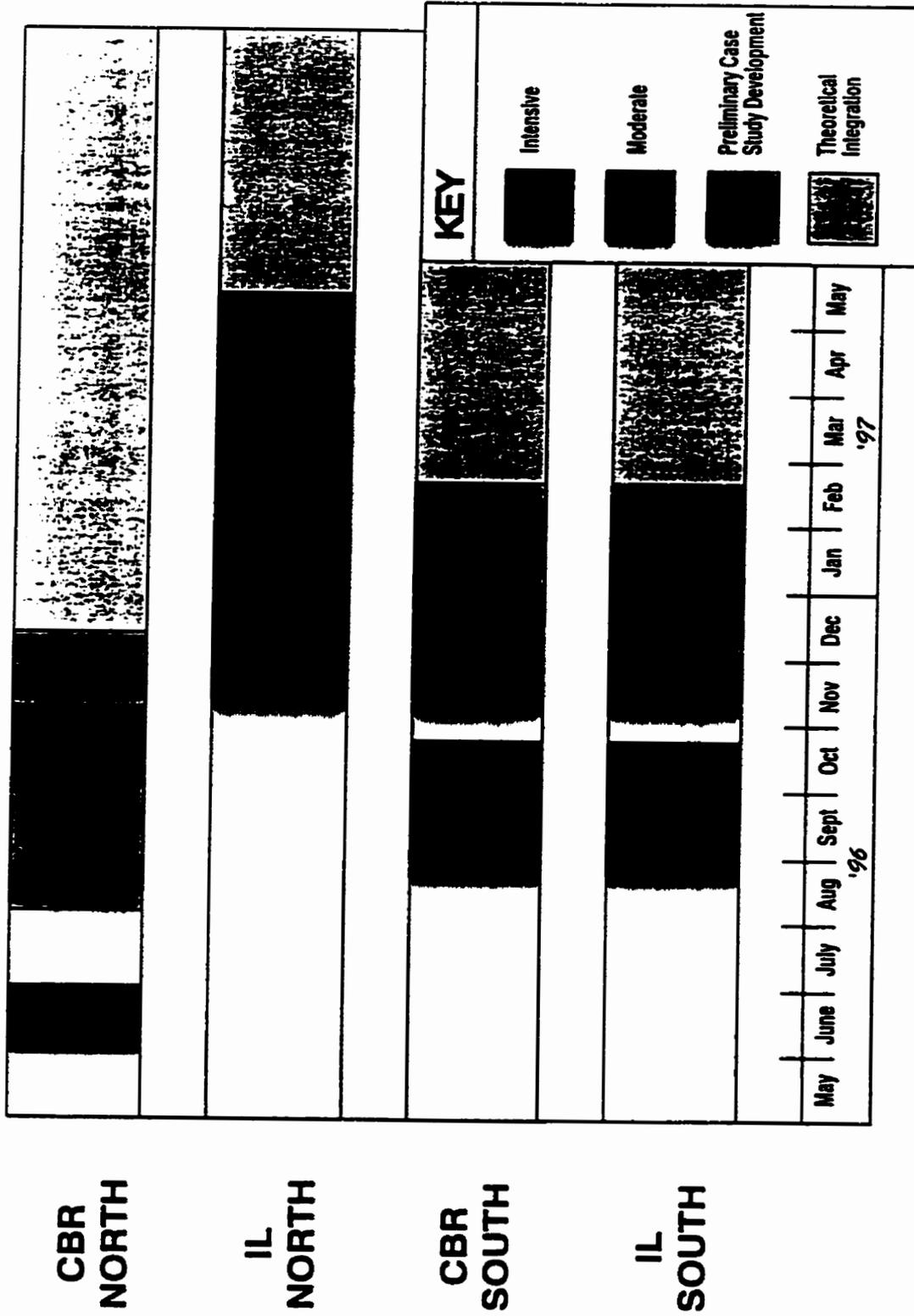
Figure 7    Chronology of Fieldwork in Research Settings

as these data were available in Winnipeg. The data collection and analysis phases in this setting were combined. This process commenced in November 1995 and was completed in April 1996.

One of the most strategic data collection opportunities was participation in international meetings and conferences. While the researcher had already been a participant in three conferences in Canada with a disability component during her doctoral research, namely, the International Conference on Asia sponsored by Studies in National International Development held in Kingston in 1993, the National Independent Living Conference held in Winnipeg in August 1994, and the Second Annual Canadian Conference on International Health held in Ottawa in November 1994, two additional opportunities for data collection presented themselves. These occasions were: the Asia-Pacific Regional Conference of RI in Jakarta, Indonesia in October, 1995, and the Evaluating Community Participation Workshop sponsored by ICACBR held in Kingston in October 1996. These events brought the researcher into contact with disability scholars, IL and CBR program managers and people with disabilities interested in international disability issues. The duration of data collection also allowed the researcher repeated contacts with key individuals. This time not only permitted the researcher recurring opportunities to check data interpretations, it also allowed an historical perspective on their interpretations to be established. Finally, it must be said that conferences as a forum for articulation of IL and CBR ideology must be understood as selective sources of data. Community based disability stakeholders who participate in and those who are excluded from such forums must be recognized.

94

Conferences provide data from an elite perspective, but this elite perspective remains important for this research because of its role in the formulation of IL and CBR ideology.

Finally, attendance at international conferences and time in the field afford participant-observation opportunities. During the time in the South especially, there were opportunities to investigate the real "impact on the ground" of community based disability projects. In a sense, observation of disability projects "in action" provided a kind of counterpart to the "talk" about disability projects found at official meetings and conferences and within archival sources. One serious challenge for the research was determining the breadth of both CBR and IL's constituency. Observation of program activities and concomitant levels of consumer involvement in IL and CBR projects shed light on how deeply CBR and IL ideology penetrated the local level. This combination of data sources ultimately permitted a synthesis of key-informants' personal experiences contextualized by culture, history, socioeconomics and politics, as well as by pragmatic and programmatic realities.

It must be acknowledged that varying data collection time horizons have an impact on both the type and quality of data collected. In general, data gathered in the South could not be as comprehensive as that in the North. One significant mitigating factor was the researcher's prior experience and contact with Indonesia and many other international informants. In the South, to some extent, this familiarity compensated for the limited time in the field.

## Ethical Considerations

Informal efforts to measure interest in the study were undertaken in discussions with CBR and disability movement/IL leaders and spokespersons during the fall of 1994 and winter of 1995. Official support was solicited from IL and CBR organizations in March 1995. Formal letters outlining the purpose of the research were then sent to participating organizations. For organizations located in Winnipeg, personal visits were arranged to seek support. Official permission to interview individuals in these organizations was granted shortly thereafter.

During this preliminary period, the research proposal was drafted. After approval of the proposal at the Departmental level, it was submitted for review by the Human Subjects Committee of the Faculty of Medicine at the University of Manitoba. Official approval from this Committee was granted in June 1995 and the study commenced.

The general organizational consent, obtained through discussions with the directors of participating organizations, permitted the researcher to access the libraries of these organizations and obtain significant amounts of IL and CBR documentation. Annual reports, position statements, media releases and program reports were typical kinds of written materials. It should be noted that a significant amount of the archival material exists in the public domain. For the public domain data, no specific individual consent procedures were undertaken.

Prior to arranging individual interviews, prospective participants were given a Study Information Sheet and Consent Form, either in writing or alternative media

format. (see Appendix C) The researcher also explained the purpose of the research and solicited informed consent. Anonymity was offered to all participants. In all but one case, this was waived. Participants were also informed that prior to publication of study findings, all comments and quotations directly attributable to any one study participant, and its context, would be provided in writing to the participant so that accuracy and propriety could be checked. Participants were also told that any portion of their remarks could be completely withdrawn at any time. The participants' preference was final with respect to changes of memory and insistence on nonattribution.

Toward the end of data collection, the researcher made the decision to not always use participant specific information in the presentation of research findings. Thus, the identities of research participants were not always revealed, even if earlier consent had been provided. This decision was made in part because of the sensitive nature of the data obtained, although this possibility was not unforeseen. The original research proposal submitted to the Human Subjects Committee for ethical approval anticipated the possibility of presenting the findings as blended case studies. Since the numbers of international IL and CBR leaders and spokespersons are so few, the source of certain information is obvious to the knowledgeable reader. A higher standard of confidentiality could only be guaranteed by maintaining anonymity.

## Data Analysis

In general terms, all data were analyzed in a similar fashion. The analysis

97

process was one in which the researcher immersed herself in the data, listening to the taped interviews, examining and re-examining the interview data. In turn, the data were transcribed, coded, and analyzed, using the constant comparative method (Glaser & Strauss, 1967; Marshall & Rossman, 1989). Through this method, important ideas, events, language and beliefs held by IL and CBR spokespersons and people with disabilities emerged. Each were assigned a specific code which represented a specific theme. The definition and categorization of these themes were continuously considered and reconsidered in light of each new piece of data.

Competing ideas and understandings gleaned from the examination of archival documents and data recorded as fieldnotes were also compared and contrasted with interview data. Data analysis was therefore an iterative process whereby new data continuously informed developing interpretations. Lupton (1992) writes:

> The extensive use of the actual textual material used in the analysis is vital, for it allows others to assess the researchers' interpretations and follow the reasoning process from data to conclusions.... The coherence of a set of analytic claims will stand itself as testimony to the effectiveness of the analysis, if both the broad pattern and micro aspects of a discourse have been explained thoroughly and with insight. (p. 148)

To be clear, the "texts" that were deconstructed in this discourse analysis included a wide range of formal and informal materials. For example, personal conversations, official interviews, published manuscripts, policy statements, and internal organizational memorandums were all subjected to critical review. While all such data were relevant sources of data in this study, they were not treated as equivalent. By

adopting a critical postmodern position for this research, a process could be undertaken that sought to determine the relative value of the various pieces of data collected in the course of the thesis research.

To the greatest extent possible, research findings use the language of the participants. Quotations from archival materials were extracted verbatim. Quotations from interviews were transcribed without change except for very light editing to make spoken language intelligible in writing. Because this research is committed to a critical analysis of the official discourse of disability rights and CBR, it is concerned with far more than the manifest context of the text however. In its entirely, this research sought "to display the reproduction of ideology, and the more subtle forms of control, persuasion and manipulation in the meanings inherent in discourse" (Lupton, 1992, p. 149).

Ideally, case study research must demonstrate completeness, evenhandedness and a thorough exploration of rival interpretations. Data collection for this research therefore continued until a plateau was reached where the researcher did not feel further data added to the central thesis. The major themes extracted through this process provided the foundations for the presentation of study findings.

## Limitations

The limitations of this study relate primarily to the practical restrictions of short term research in a cross-cultural context, and the theoretical limitations of social research employing the case study methodology.

The first limitation reflects the unilingual English background of the researcher. Key IL and CBR informants were interviewed only if the interview could be conducted in English. The language accessibility of key international disability figures was not a major issue as most are fluent in English. However, interviews with recipients of IL and CBR services (particularly people with disabilities outside of North America) were more limited, in that views were solicited only from those fluent in English. It is also important to make special mention of the validity of certain parts of interview data, again, particularly from disabled participants in the South. The problem is that some participants in CBR and IL programs may be quite unable to articulate the CBR or IL ideology within the context of an interview. Although limitations are acknowledged, these data were nonetheless included to the fullest extent possible, as they provide a significant piece of the overall research puzzle.

Second, it must be recognized that conducting the study and presenting the case, while inextricably entwined enterprises, require quite different skills. To move beyond a mere report, the literary aspects of presentation are crucial. A compelling case study, as Denzin (1994) says, must have vitality. "Writing of this order, writing that powerfully reinscribes and re-creates experience, invests itself with its own power and authority. No one else but this writer could have brought this new corner of the world alive in this way for the reader" (p. 505). The reader of the completed work is the ultimate judge of whether this sense of discovery is successfully communicated.

Finally, in the course of examining the conceptual power of the idea of community, it was impossible at times not to treat community as if it were a fixed

benchmark rather than a moving target. Every effort was made to address the

contingent, sometimes arbitrary and at other times purposeful way in which community

is defined, understood and asserted. However, the language of community obscures

intricate relationships and networks of social power. The idea of community is a

powerful tool of social persuasion. An examination of IL and CBR ideology is

therefore a useful enterprise to the extent to which it provides much needed insight into

the relationship between language and power.

# REPRESENTING COMMUNITY

## Introduction

The previous chapters have examined the evolving meanings of community and disability, and detailed the theoretical approach to the research, its design and procedures. The objective of the remainder of the thesis is to present the study findings and discuss their implications.

The purpose of this chapter, Representing Community, is to analyze the conceptualization of community by IL and CBR. The analysis focuses on the official public discourse of these models, and therefore draws heavily on written documents for its evidence. The chapter consists of three major parts. The first part shows how, for both IL and CBR, the idea of community arose in reaction to the problems associated with institutional rehabilitation. The second part describes how the historical development of these models gave rise to CBR's view of community as geographical locale, and IL's view of community as identity and belonging. The third part of the chapter discusses IL and CBR's tendency to romanticize their differential understandings of community, an issue to be examined in greater detail in Chapter 5.

Chapter 5, Community and its Discontents, investigates three aspects of IL and CBR implementation. They are: (a) identification of community needs, including the issue of community representation; (b) the process of community-building, including the issues of motivation and commitment; and finally, (c) community mobilization, which includes the selection of disability workers. Unlike Chapter 4 where archival

materials were the primary data sources, this analysis draws more heavily on key-informant interviews. Interviews are occasions for thoughtful exchange about the challenges confronting community based disability projects. Rather than representing the ideal situation as official IL and CBR documents might, these data focus on the practical difficulties related to the delivery of education, programs and equipment to usually poor and rural people with disabilities in the South.

Chapter 6, entitled The Good Society, concludes the thesis. The purpose of this final chapter is to distil the study findings and examine their applicability in other domains. The chapter consists of four sections. The first section provides an explanation for nostalgic conceptions of community. The second section speculates upon the nature of contemporary communities of geography and identity. Social policy implications are discussed in the third section. The thesis concludes with a brief summary of the key theoretical insights generated by the research.


## CBR and the Development of Community

Close scrutiny of the purpose of CBR highlights the reasons for the ideology's strong emphasis on community as the solution to disability problems. CBR was developed to deliver services to those who could not access institutional rehabilitation services, primarily for reasons of cost, but also to establish a model that would avoid some of the most significant problems associated with institutions, already well known in the North. It was known, for example, that institutions were too dependent upon highly trained professionals. Hence, CBR was developed as a practical means of

extending basic rehabilitation services to predominantly rural populations with the highest priority given to "the quantity of service coverage of the disabled population" (Menon, 1984, p. 84).

CBR developed in many different ways in different parts of the world. Hence, there is no single model of CBR. Rather, there is a tremendous heterogeneity of project styles and initiatives called CBR. While most attempt to incorporate a community development dimension, IL has remained sceptical of CBR's commitment to community development principles such as social equity and human rights -- fearing CBR represents a new form of professional domination (Enns, 1982; Friedson, 1970a; McKinlay, 1977). Criticisms of both IL and CBR are investigated in greater detail in the sections to follow. But first, a closer look at the historical reasons for the emergence of CBR.

## The Failings of Institutional Rehabilitation

The original impetus for CBR came, at least in part, with the recognition circa 1980 that while conventional rehabilitation models had expanded in the South, they would not be able to address the overwhelming rehabilitation needs in these countries (Chermak, 1990). Dr. Einar Helander was one of the original participants in the development of the WHO's model of CBR during the late 1970s. In his 1993 book, *Prejudice and Dignity: An Introduction to CBR*, Helander presents his vision of what CBR in the South ought to be. In the opening chapters, he describes the reasons for the felt inadequacy of conventional rehabilitation:

104

> The planning of (rehabilitation) services is mostly done by experts with preconceived ideas about what to do. More often than not, disabled people become passive recipients of such services. In many instances they are never consulted because the "experts" know it all.... The disabled person comes to the institution and receives training from the professional personnel there. Most of these institutions are located in the capital city. In rural areas, they are few and far between. This system should, in theory, produce services of excellent quality, even though for only a small group of disabled people. In practice, this is rarely so. This is usually because of the lack of contact with the family and the community, or due to environmental constraints such as problems with facilities, equipment, utilities or transportation. (p. 120)

Dr. Malcolm Peat has also written extensively about CBR and the role of institutions within a community framework (Peat, 1990; Peat, 1991; Peat & Boyce, 1993). While a prominent figure within international disability circles for some years, Peat, unlike Helander, was not an original participant in the development of the WHO model. Presently Executive Director of ICACBR in Canada, Peat has of late also become a leading innovator with respect to CBR in Eastern Europe. In his retrospective assessment of the historical value of institutional rehabilitation, Peat concludes this model has provided much needed comprehensive clinical expertise delivered by well-trained personnel. Peat (1990) concedes, however, that the institutional model also has some serious shortcomings including fragmented coordination of services, regional inadequacies and disparities in accessibility, duplication of services, and chronic shortages and poorly distributed practitioners.

CBR proponents in the South do not see the failings of institutional rehabilitation much differently from their counterparts in the North like Peat and Helander. For example, in his assessment of the situation in the Philippines, Periquet (1989) states,

These facilities, patterned very much like their counterparts in developed countries, are expensive to build and incur high running costs. They are operated by specialists and other highly trained personnel. Sophisticated pieces of equipment are required and when those fail to function, repairs are a problem; spare parts are difficult to find. Only a limited number of patients are served by these centres. (p. 95)

Elsewhere, Periquet (1984) adds,

Given the distance between the city-based institutions and the majority of disabled persons who live in the rural areas, many do not or cannot avail themselves of the services. Also, while the quality of services during confinement is high, the follow-up system has been found inadequate. Away from the support of the extended family and familiar surroundings, it has also been observed that patients exhibit psychologic disturbances after periods of long confinement. In countries where it is the traditional practice to have someone at bedside, confinement in an institution would result in a loss of productive time for the able-bodied companion. (p. 9)

The prominent Indian physician and CBR activist Menon (1984) agrees. He

summarizes the worldwide disability challenge facing the institutional model of

rehabilitation as follows:

The estimated total number of disabled persons is approximately 400 million, or roughly 10% of the world's population. It has further been estimated that at least two-thirds of this vast section of humanity are not exposed to any form of rehabilitation services.... In the case of developing countries, lack of manpower and finances in staggering dimensions stand in the way of providing any significant rehabilitation services of the traditional institutional type that could claim even part coverage of their vast populations. According to a special Technical Report of the World Health Assembly, the outcome of a feasibility study conducted in an African country indicated that it would take at least 60 years to develop adequate manpower and about 200 years to provide rehabilitation services to the entire population if the institutional model of service delivery is to be adopted. It is obvious that the present model of institutionalizing rehabilitation is totally inadequate to meet the problem at least with reference to developing countries. (p. 64)

106

While the diverse origins of CBR must be acknowledged, it is still the case that CBR has historically been driven by professional and institutional interests. CBR originators often work within conventional rehabilitation structures and their networks include organizations such as RI that retain an institution bias even in their models of community rehabilitation. Professional influences also shape the formulation of rehabilitation problems. For example, the inadequacies in institutional rehabilitation are often formulated in terms of technical efficiency. Thus, from the perspective of many CBR proponents, the primary barrier to expansion of rehabilitation delivered within an institutional framework is thought to be inadequate medical and financial resources, and a lack of infrastructure like transportation and communication systems to support it. However, the problems of institutions identified by health professionals and government officials are not those typically identified by the users of CBR services.

Miles (1994, November) is one of the few "CBR experts" who has documented rehabilitation "problems" from the point of view of people with disabilities. Using blindness as an example, Miles says that while a blind person needs to know whether expert medical treatment (likely found in institutions) can bring improvement, there is important related information that the specialist is unlikely to be able to provide. This lack of information often presents significant difficulties.

> If the eye specialist could not help your eyes, you still needed to know how to move around at home, how to go down the street and how to find some work that you could do. In the village, the healer knew your home situation, and could advise you and your family about everything. But the eye specialist in the city institution, might not know anything about your usual life at home. (Miles, 1994, November, p. 2).

107

To be sure, Miles is critical of institutional rehabilitation and his statement highlights its two fundamental failings. First, technical and logistical barriers prevent people from using institutional rehabilitation. This is the problem of access and distribution of resources. The insufficient supply of professionals coupled with the population's distrust of professionals only heighten the problem. Second, professional experts may not be in touch with the felt-needs of people with disabilities. This is the problem of relevance. Together, these problems led to the conclusion that expansion of institutional rehabilitation was inappropriate for the South. CBR in the community became the solution.

## Community as Geographical Locale

Developed to address global disability through an efficient approach to local disability programs linked to national health infrastructures and referral systems, the core intention of CBR is to ensure a basic level of rehabilitation service for all. For example, CBR frequently uses the administrative structure of towns and villages to organize and deliver monthly out-reach visits from hospitals and health centres. The disability/CBR component is tacked on to established health initiatives such as immunization campaigns and under-five nutrition projects, for example (Helander, 1993). Hence, CBR is not really an "innovative approach" evolving, as Chermak (1990) noted, from WHO's Health for All by 2000 strategy. Still, it was the approach thought to hold the most promise in terms of reaching the maximum number of persons with disabilities (WHO, 1981).

By committing itself to service provision and efficiency, that is, to meeting the

needs of the largest proportion of people with disabilities in the shortest possible time

and most cheaply, CBR committed itself to a geographical definition of community.

Only by thinking in geographical terms was it possible to develop a system whereby

local CBR cadres could be linked with regional health centres and health professionals

for purposes of medical referral, for example. Only by thinking about the community

in geographical terms could systems of CBR training be coordinated at village, district

and country-wide levels. The assumption of geographical community was also

necessary to design a model where CBR cadres would ultimately be assigned

households and jurisdictions for purposes of disability screening and disability

education (Poedjangga, 1991, May; Tjandrakusuma & Murti, 1992). The notion of

geographical community spatially bounded the task of CBR.

Examination of WHO documentation confirms CBR's geographical definition.

The WHO, the first international organization to launch large-scale CBR projects,

defined community in 1977 in the WHO's Resolution Concerning Primary Health Care.

> A community consists of people living together in some form of social
> organization and cohesion. Its members share in varying degrees political,
> economic, social and cultural characteristics, as well as interests and aspirations,
> including health. Communities vary widely in size and socio-economic profile,
> ranging from clusters of isolated homesteads to more organized villages, towns
> and city districts. (WHO, in Helander, 1993, p. 17)

This turned out to be a formative definition. From 1977 onward, geographical

community became the assumed community of CBR. While social cohesion premised

on the commonality of ethnic identity, language and common values was assumed present and thought to enhance CBR activities, it was physical locality that became CBR's de facto community.

Given that the aim of CBR is to "reach the unreached," it should come as no surprise that for CBR, community is largely geographical. What is less expected is that such a central concept to CBR as community has not spawned a plethora of competing community definitions, or propagated vigorous debate about its meaning. Community has not been deconstructed in this way. Recognizing the internal diversity of stakeholders and constituencies within IL and CBR however, perhaps there have been reasons for leaving the term ambiguous.

An extensive review of the CBR literature since 1977 reveals only one other published definition of community. Interestingly, this definition does not emanate from an international CBR agency, but rather exists as an aside in a relatively obscure paper by Schaffer (1991), although Schaffer himself is an experienced medical professional in international health. Schaffer's definition of community is,

> All the people in a geographically defined area within which every family *knows* every other family and wherein all *feel united* by common responsibilities, and known leadership. This would not normally exceed 2000 people. In a nomadic context it may be only 50 people. (p. 74, italics in the original)

Schaffer's definition is very similar to the definition of community offered by the WHO 15 years earlier. Both definitions recognize social cohesion or a sense of community spirit as a necessary but not sufficient condition for community. To be a community,

physical location must be its defining feature. Recalling that CBR strives to be a community development-style ideology, the scale of the geographical definition is important. Too large a population renders the participatory activities typically a part of these strategies too unwieldy. Since CBR is a service delivery model, focussed on the effective organization and efficient dispersion of personnel and resources, the geographical size and boundaries of community are central.

Unfortunately, the CBR literature provides no other definitions of community. Thus, to obtain more information about the meaning of community for CBR we must study the descriptions of CBR itself to learn what these imply. While descriptions of CBR offer an imprecise lens through which to discern the meaning of community, these instances of community are one of the few sources of insight there are.


Official Sources of CBR Discourse

One major source of information about CBR, and thus an opportunity to understand community for CBR, is the ICACBR literature. ICACBR has been actively in involved in CBR implementation around the world and also in its evaluation. A preliminary glimpse of the meaning of community is obtained from the Background Information on the CBR Concept, an annex to the ICACBR document entitled Centre of Excellence for the Development of CBR Programs for the Physically Disabled (ICACBR, 1990). In the annex, CBR is described in the following way:

> CBR is based on the principles of community development rather than a medical model and has as its ultimate goal incorporation of the disabled, wherever

111

possible, in their community as functioning members of that community. Actions to help the disabled and to change community attitudes about disability are viewed as part of the total development effort which will eventually allow the disabled full participation, social integration and equalization of opportunity. Similar to the philosophy behind primary health care, lasting social change for the disabled can only be brought about when families and communities take responsibility for that change.... Central to understanding CBR is viewing it as a philosophy rather than a program. Although there are a number of principles basic to CBR, there is no single best approach to its implementation in a particular community. One of these guiding principles is that the community itself becomes the primary resource used to provide assistance to the disabled. Community resources does not mean rehabilitation services are offered in the community (as institutional outreach) or that community members may be in some way involved in service delivery. Community involvement means bringing together different elements in community, building linkages so that a collaborative mechanism is created from and by the community. (p. 45)

Unfortunately, as an attempt to clarify the concept of community, the annex is

somewhat lacking. In this description of CBR, although the word community is used

13 times, it is never defined. Considerable clarification around the community concept

has been accomplished by ICACBR of late, the most noteworthy example being the

recent ICACBR Report by McColl and Paterson (1995, September). Yet, the early

inattention to a guiding definition of community has generated a level of confusion

around the term that continues to the present. The situation has created some

controversy too, as some factions within the IL movement see the ambiguity in the

meaning of CBR as an example of renewed professional control over matters of

disability.

Examination of the documentation pertaining to ICACBR Demonstration

Projects 1992-1993 (ICACBR, 1993) provides further evidence of what community

means for CBR. The most significant feature of note is geographical. In the Bombay

112

CBR Demonstration project for example, two rural and one urban community were selected for study. The official textual representation of community by ICACBR is as follows:

> This community consists of a group of villages, Juchandra, Kaman, Poman, Pelhar, Sativali, approximately 40 km from Bombay. The population of this area is approximately 25,000. The predominant caste of people in this community is Agris which is one of the original tribes of Maharashtra. Hinduism is the primary religion and the occupations are mainly agriculture and working in salt pans. (p. 2)

Community in this document is obviously an administrative district, defined in terms of its size (i.e., the total population) and its scope (i.e., which villages are included in the community). This description is typical. Later in the same document, a demonstration project established in Allahabad India was described as "five villages of Sirathu Tehsil of Allahabad district" and project materials stated "about a thousand families live in this area," and "around 300 families have at least one person with a physical disability.

In the North, the equivalent geographical description of CBR is exemplified by an urban program like the Yee Hong Community Wellness Foundation in Scarborough, Ontario, an ICACBR demonstration project in Canada. The scope and emphasis of this project is clearly influenced by geography. Parnes and Tjandrakusuma (1993) describe the emphasis of this project as follows:

> This project focuses on the unique demographics of this large borough of Toronto in which there has been a significant increase in Chinese speaking residents, many of whom have sponsored older relatives who now live with them and are at risk of sustaining cerebral vascular accident. (p. 6)

The purpose of the CBR project at the Yee Hong Wellness Foundation is to develop a self-sustaining stroke club and to design and produce an information pamphlet for Chinese patients and their relatives on the management of recovery from a stroke.

Published program evaluations provide yet another source of information about the meaning of community for CBR. While once again, community is never defined in these publications, it is apparent from their description that community refers to a geographical population, most often a rural village, although increasingly urban populations as well. For example, Mitchell, Zhou, Lu and Watts (1993) evaluated CBR in China and identified Guangzhou city as the community for purposes of their research. We read,

> Administratively, the city is divided into local government areas (LGAs) or 'Streets'. Jin Hua Street is typical of the LGAs in Guangzhou. The inhabitants of this community live in an area of approximately 0.44 km$^2$ within which 146 narrow and short lanes spread irregularly like a maze.... The translated ATDP (Attitudes Toward Disabled Persons survey) was administered to a random sample of 500 subjects, 250 from Jin Hua Street and 250 subjects from the control 'Street'.... There were equal numbers of males and females in the samples from each community. (p. 180-181)

The CBR examples examined in both the North and South confirm that a metaphor of space is central to CBR's assertion of community. Community refers to a population with identifiable physical bounds, whether that be a borough, an urban slum or rural village.

114

## IL and the Development of Community

In contrast to the geographical emphasis of CBR, the impetus for a new social movement of people with disabilities and their interest in the community was dramatically fuelled by the 1960s civil rights ideology in the United States and a rising consumer consciousness. Rejecting a definition of disability that implied individual deficit, they embraced the IL philosophy that held individual autonomy and self-determination as core.

The relationship between people with disabilities and the community is fraught with contradictions however. Historically, the community institutionalized people with disabilities in cases where families were unable to cope with their complex special needs. The community (meaning society) then, was in large part responsible for the widespread institutionalization of people with disabilities since the 1800s to the mid-1900s. It is interesting to note that even after the contemporary trend to deinstitutionalize people with disabilities, the community as society has still assumed a relatively minor role in advocating for people with disabilities (White, 1992). Notwithstanding the deep penetration of community language in the ideological documents of IL, society has often rejected attempts to repatriate people with disabilities back to their homes outside of institutions.

There are indeed complicated dimensions to the IL-community relationship. Nevertheless, and generally speaking, IL did grow out of a rejection of the medical model. To a significant degree, the movement's greatest historical efforts have been to resist the medicalization of disability and the institutionalization of people with

disabilities labelled sick and abnormal by medical professionals. Thus, for IL, the institution remains a potent symbol. The institution represents oppression, abuse, and medical control. By grounding itself in the ideological opposite of the idea of the institution, however, IL has been able to recapture the positive features thought associated with community. In this way, IL becomes a desirable place of mutual support, a place where a devalued identity and shaken sense of belonging can be rediscovered. Community offers hope. We examine these assertions in detail in the final section of this chapter. But first. we must investigate the extent to which community for IL is constructed in opposition to the institution.

## Defining Community in Opposition to the Institution

A wide range of policy documents and the words of IL's key ideological proponents demonstrate that an important component of the idea of community for IL is its noninstitutional nature. As with CBR, the archival materials of IL rarely provide a definition of community. Instead, the word is sharply contrasted with a very negative image of institutionalization. The World Programme of Action Concerning Disabled Persons (UN, 1983), perhaps the greatest policy achievement of international IL, provides an example of how this juxtaposition is achieved. The World Programme states,

> Many persons with disabilities are not only excluded from the normal social life
> of their communities but in fact confined in institutions. While the leper
> colonies of the past have been partly done away with and large institutions are
> not as numerous as they once were, far too many people are today
> institutionalized when there is nothing in their condition to justify it. (p. 20)

116

Institutionalization is depicted as illegitimate -- an affront to the freedom of the individual. It is simply wrong to exclude people with disabilities from participation in normal life. By casting community and institution as opposites however, one term becomes good, and the other bad.

It goes without saying that the asylums of the Victorian period are totally antithetical to the ideal of IL (Foucault, 1965; Goffman, 1961). Institutions represent societal neglect, abuse and imprisonment. Unfortunately, the worst asylums of yesterday and the best institutions of today have a tendency to become connected in people's minds as symbols of medical control (Friedson, 1970a and 1970b). The image of disabled people being historically shut away by professionals is therefore an easy one to imagine. Curtis (in Driedger, 1989) is an IL advocate who is very critical of the process of institutionalization. He equates life in an institution with "cruel incarceration" and the experience of disabled people there as "fundamentally unjust suffering." People with disabilities, according to Curtis, have been,

> killed at birth, denied education, denied the right to vote, denied the right to employment, denied the right to marry, denied the right to have families, have been sterilized, scientifically experimented upon and imprisoned in institutions under the most inhumane conditions. (Curtis, in Driedger, 1988, p. 104)

In connecting the image of the institution to medical dominance in this way, Curtis creates a powerful picture of wrong-doing systematically perpetrated on the disabled by an uncaring, able-bodied and more powerful majority. Curtis does not provide a positive alternative model however. We are left to assume that a noninstitutional

117

approach would be superior, but we are not told what form that might take.

## Institutional Constructions in the South

It is interesting to note the extent to which the meaning of institution reflects a

Western construction that has been exported, conceptually intact, to the South. An

examination of key IL documents is illuminating in this regard. The DPI Manifesto,

for example, is intended to represent the viewpoint of people with disabilities

worldwide. This document confirms that life beyond institutional walls is not only

preferable, it is natural and a right. The DPI Manifesto states: "Disabled people have

the right to grow up and live in their natural environment. We therefore reject all

forms of segregation, and we refuse to accept lifetime isolation in special institutions"

(DPI, 1982, p. 54). In another DPI document, the Statement on Equalization of

Opportunities (DPI, 1987, January), we also read how institutions prevented people

with disabilities from being involved in the mainstream of society life, and apparently,

only recourse to community living can remedy the wrong:

> Traditionally, disabled people have been warehoused in institutions in the
> Western world, and in some of the developing nations. Because of this,
> disabled people have been cut-off from the mainstream of the community. To
> participate fully in society, disabled people must live in the community like
> everyone else.... Institutions most often are sterile and impersonal places where
> disabled people have little privacy and control over their person lives. (p. 4-5)

These excerpts from DPI materials are interesting for several reasons. In the first

place, by claiming that the process of institutionalization cuts people off from the

118

mainstream, the separation between the community and the institution is enlarged.

Second, as life in the community is the only life thought to be normal and natural, it

logically follows that institutional life is not. Community offers the superior life;

institutional life is not only inferior, it is removed as a legitimate option entirely. There

is plenty of additional evidence to suggest that IL maintains a sharp separation between

institution and community, both at the level of actual human groups and at the level of

ideas. For example, in her historical account of the emergence of DPI, Driedger

(1988) describes the extent to which DPI opposed institutions this way:

> DPI believed that no person should be institutionalized because it was like being
> imprisoned for life. It contended that independent living in the community
> should be encouraged everywhere.... Many of those who lived in institutions
> experienced beatings and sexual assault, and were prescribed drugs to keep them
> passive and easier to control in an institutional setting. DPI considered such
> treatment torture, and inhumane and degrading treatment. (p. 105-106)

IL ideological leaders hold institutionalization in such contempt, that for some activists

in the South, it is difficult to accept the Western articulation of IL. Because Southern

countries lack the basic medical and social safety net assumed in the Euro/North

American system however, IL in the South has as one of its prominent goals greater

attention to disability by the medical profession and national health ministries, not less.

The issue of institutional rehabilitation is a complex one and disability activists in the

South do not wish to become alienated from their supportive allies in the West. The

socioeconomic differences between the two contexts are so substantial however, that at

times, these relationships can become strained. An example of this tension was

119

revealed in an international IL survey undertaken by the World Institute on Disability

(WID) in Oakland, California in 1995. WID surveyed member organizations on the

status of IL in their countries. While the survey findings suggested that overall,

organizations in the South have managed to sustain small voluntary disability projects,

the socioeconomic challenges they confront are significant. The following comments

received as part of WID's International IL Survey provide a glimpse into the situation:

> We have no finances for Independent Living but our priorities are education of
> children and development of technical devices (Cameroon).
>
> The disabled are a burden to society, even family. If the family is poor, the
> person with a disability may be deserted (Madagascar).
>
> The concept of independent living is not entirely the same as the U.S. concept
> owing to the lack of funding support from the government. Disabled people
> have to fend for themselves. There is nothing in financial support from the
> government (Philippines). (WID, 1996, p. 8)

Southern countries are not the only countries having difficulty mobilizing resources for

health and disability. Eastern Europe has also become a world focus for humanitarian

efforts as political structures and social institutions have crumbled under conditions of

civil unrest. The situation of people with disabilities in Romania is illustrative. In

response to WID's IL Survey, the Romanian respondent wrote,

> The increased international attention on Romanian orphanages somewhat
> overwhelmed the national psyche. There was international embarrassment, and
> it led to denial and de-valuing of the lives of the disabled. Even now, constant
> images of HIV, street children, etc. It creates a backlash against historical gains
> in disability attitudes. (WID, 1996, p. 10)

The same respondent continued,

> It was and still is shameful to have, know or be a disabled person. There is legislation dealing with disability and there is even an elaborate network of services. But they are paternalistic. The concept of protection is still central. It is not integration. Today, change is very slow because of the crippling economic situation. People with disabilities are very dependent upon their families. Economic competition is so great and society support so minimal that disabled persons will fail without significant individual courage. (WID, 1996, p. 9)

David Werner is a prominent international disability activist who appreciates the challenges confronting those dedicated to improving the lives of people with disabilities worldwide. Werner, who has a medical background and a mobility disability, has played an integral role in bridging the community-institutional rehabilitation divide (Werner, 1985 & 1988). His famous books, *Where There is No Doctor* and *Disabled Village Children* have been translated into many languages and are today mandatory reading for everyone interested in international disability.

Werner's approach incorporates a strong community development focus with education and communication assuming prominence. Werner also stresses the idea of appropriate technology development as the key to disabled people's social and economic success. Werner has always been an outspoken critic of conventional rehabilitation strategies that have aimed to replicate institutional programs in the South. Examination of Werner's viewpoint therefore provides important clues about the meaning of community. In a speech given in 1994, Werner provided a stinging indictment of traditional rehabilitation:

121

> Unfortunately, most services for disabled people remain very institutionalized
> and top-down. Delivered by costly professionals in hospital or large urban
> centers, they reach only a tiny portion of those in need. Many of these palatial
> urban centers are equipped with all the most modern, expensive therapeutic
> equipment, imported from the North. Too often, however, much of the therapy
> executed on disabled clients tends to be at best ritualistic and at worst,
> counterproductive. Even special seating is often thoughtlessly standardized:
> children of all sizes and disabilities are strapped into oversized chairs that
> increase, rather than help correct spasticity and deformity. In some of these
> institutions you get the feeling that disabled people are lovingly dehumanized,
> on the assembly line of an elaborate robotics factory. (p. 2)

Werner's words are deliberately aimed at medical personnel who work in centralized

rehabilitation institutions while claiming a community and IL focus. His criticism of

institutional rehabilitation must be understood in this context. But again, by vilifying

the institution, the status of its opposite, the community, is enhanced.

There can be no doubt that the collective experience of those people with

disabilities who were institutionalized was a powerful force on the eventual founding of

the disability movement worldwide. Furthermore, it is not unreasonable to expect that

the evils of institutional life motivated an embrace of everything institutions were not.

In this way, community came to symbolize all that was desirable about the goals of the

disability movement. It got disabled people out of institutions, and perhaps more

importantly, reinstilled a long absent sense of autonomy and self-determination. The

groundwork for a political movement was thereby laid. By defining their movement in

opposition to the prevailing institutional and medical discourse, people with disabilities

established not only their own community of identity, but established a legitimate place

for themselves in the community as society. This had the significant effect of

increasing the moral goodness of the idea of community.

## Joint Constructions of the Discourse

The IL movement is not exclusively anti-institutional. This is an important

point. There are less polar dimensions of the disabled consumer discourse. There are

instances, albeit infrequent, where the utility of institutional facilities is recognized.

These instances have historically also been the occasions for joint construction of the

disability discourse. In other words, both the disabled consumer agenda and the

professional rehabilitation agenda were addressed in the representation. For example,

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities

states:

> All persons with disabilities, including persons with severe and/or multiple
> disabilities, who require rehabilitation should have access to it.... All
> rehabilitation services should be available in the local community where the
> person with disability lives. However, in some instances, in order to attain a
> certain training objective, special time-limited rehabilitation courses may be
> organized, where appropriate, in residential form. (UN, 1984, p. 19)

In a second example, The World Programme of Action (UN, 1983) states:

> Rehabilitation services are aimed at facilitating the active participation of
> disabled persons in regular community services and activities. Rehabilitation
> should take place in the natural environment, supported by community-based
> services and specialized institutions. Large institutions should be avoided.
> Specialized institutions, when they are necessary, should be organized so as to
> ensure an early and lasting integration of disabled persons into society. (p. 6)

These joint constructions illustrate that IL does not explicitly rule out the possibility of

123

institutional services in some cases, as long as those cases are clearly demarcated.
Complete endorsement of institutional rehabilitation services is, of course, out of the
question. To avoid the slippery slope back to the acceptance of institutionalization, IL
must take a firm stand against the penetration of professionals and institutional
structures into the lives of disabled people. Indeed, there is some evidence to suggest
that the movement is committed to a complete separation between professional
rehabilitation and community services and IL. The revised DPI Constitution adopted in
1993 lays down the guiding principles for the international disability movement. The
Preamble to the Constitution reads as follows:

> Whereas rehabilitation is a process aimed at enabling a persons to reach an
> optimum physical, mental and/or social functioning level in order to provide
> that persons with the tools to direct his/her own life, independent living and
> community services are not and should not be, part of that process. (p. 1)

Community and institution therefore attain their present status as mutually exclusive
categories. As Derksen (1980) points out, this position is imperative for the IL
movement because "only by limiting the rehabilitation concept to a treatment model can
disabled people assert themselves in society as healthy, and normal" (p. 3). By placing
professional rehabilitation on one side and contrasting it with IL and community
services on the other, and by emphasizing the most unfavourable attributes of
institutions, all conceptualizations of community are rendered very positive indeed.

124

## Community as Identity and Belonging

Analysis of the IL discourse provides many important clues to the meaning of community. First and foremost, IL sees itself as a social movement. Unlike CBR, which sees itself as external to the community, an approach applied *to* the geographical community, IL sees itself as an integral part *of* the community. As a result, there are important differences between what community means to each.

First of all, for IL, community is a symbolic place where personal identity and a sense of belonging can be found. This is achieved through members' collective efforts to share their disability experiences. A new sense of unity and cohesion emerges as members of the movement also mutually reinforce each other's feelings about the moral correctness of the cause of disability rights. Disability activists interviewed for this research from North and South similarly agreed that the element of shared experience is a critical component in the generation of identification with IL. Ron Chandran-Dudley, a Fulbright scholar and graduate of the London School of Economics, and the Founding Chair of DPI says,

> I really feel our empowerment is what legitimizes the disability movement. The acceptance of each other is where the power of the movement rests. And within that, we want to show that people with disabilities have capabilities, to play a role in their communities and to be accepted by their communities. Everybody has to have a sphere of influence. Why is it that the women's movement has this amount of recognition, this amount of power? I believe that is because, first and foremost, it had communication, woman to woman, like the movement of the socialists. If you didn't have the workers coming together, they were isolated and they came under their parents, their lords, their masters, their shahs. But when the workers began to link up together, whether they were in the peasantry or otherwise, they began to find a lot of power!

125

While Chandran-Dudley does not say precisely what community means to IL, it is clear from his statement that identification with like others is a prerequisite. Shared understanding and support are also necessary ingredients for people with disabilities "to play a role in their communities and to be accepted by their communities." The importance of shared personal experience is so central that it is nearly impossible to belong to IL without being disabled oneself. A young disabled man and former employee of DPI in Winnipeg states,

> I do think that personal experience of disability is very important. Or, an ability to listen and accept people's own definitions of themselves. That's very difficult for everyone to do -- to listen to a person and accept their definition of themselves, without arguing with them. No judging. Who am I to say this is your experience of disability and this is what you need? Because that's the point, you see. The point is that the movement validates all the concerns. It is the same with the women's movement, and the Black civil rights movement, the Black power movement. It is the same as anticolonialism. The movement is there to validate all the concerns of individuals. It is like a safe place. So, if a person who does not validate those concerns comes into the movement, it won't work. And that person won't be there long.

The community is certainly a place of solidarity and support if "the movement is there to validate all the concerns of individuals." Apparently then, the community of disabled people is not judgmental either. It welcomes those who wish to belong, albeit on the condition that individuals sufficiently embrace the principles of the movement.

In addition to providing a place of identity and belonging, the idea of community serves to inspire people with disabilities to recommit themselves to "the cause." Irene Feika, a prominent Canadian disability activist and representative of DPI, spoke at the World Congress of DPI in Vancouver. She said,

126

> I believe that one day history will look back on us and realize ... we began to take back control of our lives. No longer will we, as people with disabilities, tolerate being treated as second class citizens.... Today, and in the days to come, we can and will make a difference. The days will be long and the work will be hard. At times we will feel exhausted and wonder if the effort is worth the results. We can make it worthwhile for the knowledge and skills we depict are many. The countries and cultures represented in this room are numerous and diverse. Under other circumstances, these differences might prevent us from working together, but the commonality of disability unites us. Our concerns, our issues, and our solutions may vary at times and yet, our similarities should enable us to overcome all the barriers in our way.... By sharing our ideas and experiences we can become stronger. We are in a very powerful position to raise a "Voice of Our Own." Let us be heard around the world! We will be heard and listened to for we demand our rights as citizens as full and participating citizens. United we stand strong! (DPI, 1992, p. 7)

The words of Feika and other prominent IL leaders have a real and powerful effect on the formation and ongoing survival of the disability movement. While there are very real resource challenges that continue to frustrate the emergence of any comprehensive expression of IL in the South, there is also a fragile network of DPOs that continues to represent their interests (Solo CBR Workshop, 1995). This small network of indigenous disability project managers, academics, medical personnel and NGO directors continues to struggle to ensure a place for disability on the agenda of national governments and international humanitarian organizations and aid agencies. The strategic assertions of community by prominent disability activists and elite organization leaders have been essential in this regard. While the notion of community has not always been explicit, it has played an integral role in constructing a better model for disability and rehabilitation services in the South. These assertions stress community relationships based on social justice. Feelings of belonging and solidarity

are emphasized, and by implication, the sense of belonging to a community that cares about the situation of disabled people is strengthened as well. Individuals who chose to align themselves with international efforts to enhance the lives of disabled people are thereby inspired to do more. Community for IL is hence a place of success and power for people with disabilities.

## Official Sources of IL Discourse

In addition to generating enthusiasm and commitment within the IL movement, there is strong evidence to suggest that IL is concerned with building a solid relationship with society. The first step toward this relationship is accomplished by stressing the idea of community. The argument of IL therefore proceeds essentially as follows: Community is essentially good, so belonging to any community is good as well. It follows that since society consists of a collection of diverse communities, then recognition of diversity (including people with disabilities) should lead to increased solidarity between all communities, and this increased level of solidarity within and among communities is good for society overall.

Rachel Hurst is a British woman and longtime wheelchair user as a result of congenital muscular dystrophy. She is also a spokesperson for Disabled Awareness in Action in London. In her role as a disability advocate, Hurst plays an important role in influencing public attitudes toward people with disabilities. At the 3rd World Congress of DPI, Hurst chaired a special forum focussed on the power of media in shaping attitudes about disability. In that forum, Hurst put the argument articulated above into

128

action. She proposed that all of society is characterized by diversity, and since

diversity related to disability is just another kind of diversity, it too should be

accommodated. Hurst made this argument in the following way:

> There has been a long, long history of the negative portrayal of disabled people.
> In western folk tales the wicked witch or evil person is always portrayed with a
> crooked back and using a stick. Tribal societies talk about the disabled person
> as being be-witched, possessed of evil spirits. Religions emphasize disabled
> people as bearing the burden of sin. These images have had a profound effect
> on how the world has looked at us and treated us. They have ensured that we
> are seen as different, as social outcasts. We are a people who, because of our
> differentness, must be treated differently. What is even worse is that we are
> expected to behave differently too. We cannot be ordinary people -- we have
> several stereotypes to fulfil -- we can be pathetic or passive, or we can be brave,
> smiling through the tragedy, or super heroes overcoming appalling adversity.
> Because of the continual drip-feed of these images by the media and by social
> conditioning, it can be very hard for many disabled people not to conform to
> one or another of these images.... We can, of course, try to become like a non-
> disabled person and appear to be more acceptable. If we make a real effort, no
> doubt we could really completely alter our whole being and fit into the present
> structures, just as women are often seen as having equality if they behave like a
> man or ethnic minorities become acceptable if they accept as theirs, the whole
> cultural and social structure in which they live. This is plainly absurd. Society
> needs difference and color and variety and each human being should have the
> right to contribute his or her uniqueness. So, it is not the individual who should
> change, it is society that must adapt.... And we must get this definition of
> disability across. Until it is grasped that we are perfectly ordinary members of
> society with our own particular, very valid characteristics, we will never fully
> participate in our own communities.... Women and black people have also said
> to the world: "We are a people in our own right, a people who cannot change
> but for whom society must give equal opportunities and right to full
> participation.... If the media can portray a society in which disabled people are
> fully and equally participating, then they will reflect what a society should really
> be. If our talents and contributions are fully recognized, then the world will
> benefit. (DPI, 1992, p. 28-29)

The community of everyday life is where the disabled and able-bodied intermingle.

Community therefore provides an ideal opportunity for the abilities of disabled people

to be noticed. For IL, this is clearly an objective, because a world that recognizes and welcomes different abilities is thought to be indicative of a good society.

In another textual example from DPI literature we read as follows:

> The rapid expansion of DPI is a reflection of the enthusiasm and commitment of its members. A popular DPI motto is: "No one can stop an idea whose time has come." The time has indeed come for disabled people to gather from around the world to create a united voice. Through DPI, this voice has already made a significant impact, not only in regards to disability concerns, but also on issues of justice, human rights, peace and international development. *The benefit is shared by everyone* [italics added]. (DPI Overview, undated, p. 1)

Here again, by creating the impression that "we are all in this together," and that reliance upon each other is the key to satisfying relationships and productive lives, IL attempts to foster a bond between all members of society. Ultimately, the movement promotes the idea that through mutual support, social justice will prevail. There are further examples. James Derksen, a founding member of the Canadian disability movement, describes how IL is able to create an atmosphere where the similarities between all human creatures is emphasized. Derksen (in Driedger, 1988) says,

> I sometimes think human society is asleep and dreaming a dream where some people are perfect, beautiful, and powerful and others are flawed, unbeautiful and powerless. In the dream the perfect people play their immortal parts and the imperfect people are rejected from human life. We are helping to awaken humanity to the reality that all people are flawed and yet beautiful, and each one limited in his or her unique way and yet powerful. (p. 115)

Derksen suggests everyone in society is in some way disabled. Diversity thereby unites all humanity -- the boundary between the able-bodied and people with disabilities

130

effectively disappears. Thus, the first step in securing equality for disabled people rests on the notion of commonality, not difference.

The emphasis on the idea of community is understandable as these textual examples represent the primary means by which IL lobbies for social change. Embodied in policy documents and speeches generated in the late 1980s and early 1990s, rights rhetoric was a purposeful strategy meant to push nations, organizations and individuals forward in their thinking about disability. Rather than dwelling on past injustice and tragedy, these initiatives represent deliberate attempts to secure an improved future for people with disabilities through social policy formulation and legislative change.

The alliance between people with disabilities and the able-bodied majority is not illogically couched in community terms. The geographical community is where we all rub shoulders, and the conceptual fluidity of the term allows IL to capitalize on the idea of a sense of community as well. IL seems to suggest that through physical proximity, similar attitudes are developed too. Could it be however, that *inter*dependence and not *in*dependence holds the key to the diversity issue? People with disabilities interviewed specifically for this research seemed to think so. A young woman with a visual disability who is an occasional volunteer with the Winnipeg Independent Living Centre stated, "Nobody gets anywhere on their own in life, no matter how independent they think they are, or strive to be. We are social creatures and we have to work together to help each other out."

This is an issue of considerable interest in the South as well. During the IL-

CBR Seminar organized by WID at the Asia-Pacific RI Conference in Jakarta, Samir

Ghosh, the Chairman of Rehabilitation India, an indigenous NGO stated,

> Independent living need not mean that I live alone and also get socially
> ostracized. When we talk about IL in India, what comes into most of the
> people's minds is: "Don't you know we rather believe in interdependent living,
> rather than independent living?" That is, helping each other at all times. Here,
> there is more of a community feeling. There is a very strong feeling of
> community within the country. And there is a very strong family values system.
> So, I want to endorse the view of my friend from Cambodia who has brought
> out this point very clearly. Independent living does not mean that I live
> absolutely on my own and there is no need for anyone to help me.

Yi Veasna is in the unique position of being the Cambodian RI delegate in the Asia-

Pacific Region and also the national DPI representative. While dual representation

within the network of professional rehabilitation and DPOs is not typical in the North,

it is not atypical in the South. Veasna provided additional support for the notion that IL

could strengthen its relationship with society generally by adopting the principle of

interdependence. He made his point by referring to the experience he had upon arrival

at the Conference hotel in Jakarta. Veasna said:

> When I arrived at this hotel for the first time, I was very happy because
> everything is accessible. They have done this for me. But there is one
> exception, in the bar. They have no ramp. I wanted to go to the bar, so my
> friend, he lifted me to the bar. But after they saw that, they put the ramp up for
> me. This is independent living! It is okay if people help me, but I don't want
> them to lift me every time.

After sharing this example, Veasna expounded upon the importance of the IL

philosophy more broadly:

132

If I have IL, accessibility for my house, accessibility in public places, then I have opportunity. I have participation. When I have participation with other people, I get more knowledge and gain some experience. I develop my capacity. I get some more education. And when I have more capacity and more knowledge, I come to the non-disabled people sitting in my wheelchair *but my ideas are not disabled!* I can read, I can write, I can answer, I can speak to you. This is one part of IL. I want to say that I am a disabled person, but I have been able to *do*. (emphasis in the original)

There is evidence in the IL literature of broader agreement for a reorientation toward interdependent living (Condeluci, 1991). For example, the editor of the European disability magazine Helioscope recently wrote,

We all need some kind of aid at various stages in our lives. Short-sighted people see with the aid of glasses, and the translation which makes this text available in every [European] Community language is an aid too. Yet no one would think to label a short-sighted person, or a German who does not happen to understand Spanish, "disabled." We must reject the assumption that we are all disabled, and rather think of ourselves as free citizens with diverse requirements for achieving independent living. (Aguirre, 1995, p. 1)

Therefore, while IL supports the right of all people to control their own lives, they also support an ideology that strongly implies that affiliation, cooperation and mutual assistance (i.e., interdependence) are the means to achieving this goal.

The first two major parts of this chapter are now complete. The evidence for the development of the conceptualization of community in opposition to the institution has been presented. CBR's tendency to view of community as geographical locale, and IL's view of community as identity and belonging have also been established. The final section of this chapter, Disability and Romantic Community, examines the potential consequences of these views for the meaning of community.

133

**Disability and Romantic Community**

Community has rarely been defined by IL or by CBR. When meanings are left vague and ambiguous however, the word community is used by various community stakeholders, either naively or with strategic purposes in mind. The idea of community is so malleable that even apparent competitors find this concept useful. Most often the connotation of community is positive -- perhaps because nostalgic feelings for a better past seem to hasten the attachment of good community features to any group calling itself a community in the present -- an argument that will be developed in the final chapter of this thesis. To conclude this chapter however, it is necessary only to see how sentimental the international disability discourse can be with respect to community. Whatever the ultimate explanation for representations of community are, both IL and CBR are clearly enamoured with the idea.

Romantic Community and CBR

Generally speaking, CBR presents itself as a community based model of disability service provision. However, CBR appears to view and treat community as something more than a geographical population awaiting rehabilitation. At times, CBR seems to assume that communities are somehow pure and that local community efforts at improving life conditions are in some way noble. This view has significant implications, not only for the way CBR programs are delivered, but for their ultimate success as well.

An examination of archival CBR materials provides our first glimpses of CBR's

134

tendency to romanticize the geographical entity called community and the endeavours

undertaken by community members. For example, in an article published in CBR

News, community life in India is depicted in the following way:

> A village in a developing country, untouched by so-called "village development"
> is a self-sustaining entity which has within it, its own medical system and other
> systems in a harmonious balance. Such a village has its own method of looking
> after the disabled people. The disabled individual may be liked or detested by
> some, but yet will be accepted by the village community. Some crude device
> for mobility may have been devised for ambulation by the bicycle repairer; the
> can artisan will have made crutches; the practitioner of rural medicine will have
> provided locally made medicine. If the individual is disturbed mentally she/he
> may seek help from the village priest (*pujari*). If self-sustaining mechanisms
> already exist in every village, what can be done to reinforce these and to make
> them more effective. (Banerji, Banerji, Banerjee & Srivastav, 1992, p. 5)

Village life here is presented as peaceful and satisfying. Community members are well

known to each other and care for each other. There is no hint of dissent or conflict. In

another example, community life in Mongolia is depicted this way:

> Many people who have never visited Mongolia nevertheless have romantic
> images of the beauty and vastness of their remote country and of its proud and
> secret people. Such images date back to the time when Ghengis Khan and his
> successors extended their empire to be the largest on earth.... Mongolia today
> is still a vast country ... with enormous stretches of beautiful steppes, mountain
> and desert areas where traditional herdsmen on horseback attend to their animals
> as they have done for centuries.... A large part of the population are nomads
> who move several times a year to find the best grazing for their herds of horses,
> cattle, sheep, goats and camels. The traditional nomadic lifestyle, well adjusted
> to harsh living conditions, depends upon participation of all family members,
> even the youngest ones, to ensure survival. (International Rehabilitation
> Review, 1994, p. 24)

These two examples illustrate stereotypical, one-dimensional accounts of community.

The community depiction focuses only on community support; it does not focus on kin conflict or witchcraft accusations which can also be very real elements in the South. The reader is left with a sentimental impression about the struggles and risks of everyday life. The reader is also encouraged to believe that survival within these primitive contexts is ensured only through the mutual interconnectedness of all community members. While there may be an element of truth in this, we can be equally certain that the use of the language of community in this way perpetuates sentimental understandings. These examples of cross-cultural discourse decontextualize the reality of heterogeneous communities in the South. These depictions are not full ethnographies. They do not incorporate the breadth and fullness of social relations. Examples abound in the international CBR literature that describe countries and communities in such ways. These examples all show that medical professionals and disability advocates alike use selective interpretations of the community. As a result, we are left with the impression that communities in the South are primitive, mutually caring, homogeneous and egalitarian.

Earlier in Chapter 2, it was argued that the word community generates images of primitive and natural places, inherently less evil than the modern world. In small rural communities, people are thought to be close-knit and supportive of each other, places where positive things happen. Could it be that people in the South are thought to be untouched by modern development, and thus more moral? This seems rather remarkable. It belies a sort of natural innocence that people in the South are thought to possess. This attitude is especially evident in discussions focussed on disabled

136

children. Dr. Laura Krefting, an anthropologist and disability advocate now living in Southeast Asia, is concerned that many well-intentioned people come to the South expecting to find people "so much more willing to help each other" than anywhere else. In particular, she claims European and North American funders and disability project managers have very unrealistic expectations about the conditions in rural Southern villages. Krefting states,

> I think the community is being sold as primitive and good in developing countries. Like National Geographic's community. Everybody wants to go and see the community! I think there is a real expectation that there is much more mutual self-help, more extended family, and farmers running around giving their rice to poor people. It just isn't so.

If CBR practitioners expect communities in the South to be more supportive to their members than communities in the North (because they view Southern communities as more primitive and even more good), then it logically follows that rural villages should be the most positive places of all. After all, rural villages possess the most traditional features of all. They represent a stable population whose members are well known to each other. In addition, because rural villages tend to be economically reliant upon agricultural production, at least some basic system of social support is expected to be in place to deal with crises adversely affecting the harvest or food supply. From textual examples of CBR discourse, it appears that there is a differential expectation with respect to the behaviours of rural and urban populations in this respect. Based on these expectations, the rural village is seen to be the preferable place to implement community based disability projects. Experienced project managers in the South state,

137

> Rural communities are more compatible for CBR from an ideological point of
> view because they have more formal structures, are culturally homogeneous and
> close-knit with good social support systems like joint families. Such
> communities are mutually supportive of each other.... Urban slums on the other
> hand are difficult to define and demarcate. They are heterogeneous and
> disorganized like a patchwork quilt. Urban slums have a floating population,
> are politically sensitive and usually have no consistent formal leadership.
> (Abraham, Panackel & Thomas, 1994, p. 97)

In sum, rural geographic villages are believed to possess positive characteristics that urban communities do not. When the word community is used then, attributes of an ideal form of community are applied to human populations in the present.

The way in which CBR conceptualizes community has profound implications for the way in which CBR is implemented as well. First, if geographical communities are seen as mutually supportive entities committed to local improvements, then efforts to strengthen these bonds will be undertaken and viewed as worthwhile. Second, because community members are thought to care for one another already, participation in CBR programs is assumed to be easy to strengthen and sustain. Finally, because communities are seen as egalitarian and cooperative structures, democratic participation around community based disability activities and decision-making is thought to be a familiar process. Once again, evidence from CBR discourse bears out these speculations. Helander (1993) provides a typical description of CBR implementation. His description suggests how unproblematic the process is thought to be. Helander states,

> At its inception, a CBR system will necessarily be simple. Over time it should
> be upgraded from below, by improving community workers' competence
> through in-service training programmes. Similarly, parents or other family

138

members who act as trainers of disabled individuals could develop their abilities through experience. Local school teachers could learn more about how to integrate disabled children in the class, possibly with the assistance of a mobile resource teacher. Community leaders could start projects for integrated, informal vocational training and help disabled people to find an income-generating activity. Human rights could be protected if the community provides mediation. And disabled people could obtain more say and better representation of their views. CBR programmes owe much of their success to the principle of building and upgrading the system from below. (p. 92)

Helander suggests that the process of community mobilization is fairly straightforward. For example, there is no indication that some factions within the community might not be interested in CBR. As we will see shortly, this is not always the case. In fact, the implementation of CBR projects may be far from ideal. Many projects are distinctly top-down in the sense that hierarchical administrative structures, health professionals and even community development experts lay out the CBR plans and orchestrate all aspects of its implementation. Thus, the ideal of grassroots participation is often absent.

Helander's description of CBR also assumes strong participation from prominent community leaders. Recalling that CBR tends to approach disability project implementation in a geographical way, it is logical for CBR to identify teachers, religious leaders, political officers and other significant community stakeholders as essential people to be involved. Disability awareness training and basic medical rehabilitation techniques are often targeted at these groups. Individuals from these groups are also frequently identified, either by the village as whole or by village leaders, to serve as frontline CBR workers. Their function is crucial to CBR success,

as a senior CBR administrator in Indonesia, Dr. Arief Haliman confirms:

> If you want to do CBR, it doesn't have to be everybody, but you need the
> sparkplugs. You need the leaders, you need the drivers. In a successful CBR
> project, they are absolutely crucial. If you don't have them, it doesn't work.
> And by heart I mean you have got to have compassion for the people. You have
> to have the understanding. If it is truly a community development approach, the
> more you get into it, you must pay attention to the need. Otherwise, it is just
> service delivery.

The idea that people will participate in CBR and be committed to it is an assumption,

however. It is an assumption based on the presumed qualities of the community and its

members. Still, this is the conclusion one would reach when community is understood

and represented by CBR in the way that it is. Lele and Dalal (1993), in their analysis

of CBR however, are not nearly as convinced that the positive images attached to

community by CBR accurately portray the reality of contemporary communities. They

say community is often presented in a way that,

> projects idyllic images of mutual support and cooperation. It evokes in our
> minds a place of residence of a small number of households where everybody
> knows everybody else. People understand each other, share each other's
> sorrows, aspirations and dreams, and have a common memory of past struggles,
> hardships and celebrations. Caring for each other forms the core of this idea.
> (p. 2)

Momm and König (1989) too, in a rare example of critical thinking by an international

intergovernmental health organization, believe there is a significant propensity on the

part of CBR planners to idealize community. They say CBR planners,

> tend to work with the vision of the ideal village which exists with only minor
> modifications in the same way in all parts of the world. This model village is

140

characterised by a sense of community spirit, harmonious relations between people, the desire to help one another and to take decisions jointly, all community members being equal. Such villagers are notoriously happy people, in harmony with themselves and their environment, they live well from the land which they own and they are all filled with the concern to look after the community member in need of assistance. (p. 3)

The depiction of community identified by Momm and König is rather unrealistic.

Although there is a growing awareness of the tendency to view community as good,

professionals, government officials and funders employ the word widely. When

community is represented in such an overwhelmingly positive light, whether intended

or not, the community is likely understood to be something it actually is not. Vanneste

(1994) puts it this way:

To some people, CBR is becoming a myth in which "the community" is the superpower that will make sure "everything is going to be OK." It is an ideology, in which one finds the typical roles of the good (the disabled, their family and community members), the bad (doctors, specialists, directors) and the ugly (institutions, centres, money). Within this ideology, the "community" is not just the *place* where the rehabilitation takes places. It seems to be the *ultimate place*. (p. 2, italics in the original).

The firmness with which the idea of essential goodness of community can take hold is

startling. The belief can be so strong that individuals believe that any problem arising

in conjunction with CBR implementation cannot possibly be the fault of the community.

Problems must be attributable to another source. Dr. Enrico Populin, Chief Medical

Officer of the Rehabilitation Programme WHO, has recently written "When CBR

projects are in conflict, it is not because of differences in communities, but because of

differences in the ideology of the people who initiated the project, and who have not

141

allowed the communities to have control of the activities" (Populin, 1995, p. 4).

Populin is claiming that if only "the community" was in charge, things would be fine.

Populin is also assuming that villages have the power to define disability projects and

manage their activities. While this is the ideal of CBR projects, it is much rarer in

practice. It is more frequently the case that medical professionals and health officials

design the CBR project, and community members participate as determined by these

individuals in conjunction with local leaders.

Allowing a mythology of goodness to prevail risks ignoring the fundamental

reality of communities. Miles (1994, November) says CBR has, for some time, held a

very romantic vision of community. CBR advocates tend to view ordinary people as

"idealized, self-reliant, mutually caring local communities exercising their right to self-

determination, restructuring their lives and reorganizing their resources so as to become

healthy communities fully integrating and valuing members with physical and mental

impairments" (Miles, 1994, November, p. 1). However, Miles also stresses, "in

practice, ideal societies have nowhere emerged or been found, constructed, or

consolidated" (p. 1).

Finally, there are other high-profile publications that provide further evidence of

a sentimental view of community. The ILO/UNESCO/WHO Joint Position Paper on

CBR released in 1994 is one such publication. The Position Paper makes frequent

reference to community, although for the most part, the references are made in relation

to the aims and implementation strategies of CBR. For example, "CBR requires upon

governments to transfer responsibility and necessary resources to communities so that

142

they can provide the basis for rehabilitation" (p. 2). As Miles (1994a) once again

argues in his critique of the Position Paper, "most governments in the world have *not*

*yet taken up* responsibility for the rehabilitation of disabled people -- so it will be hard

for them to *transfer it*" (p. 3, italics in the original). While CBR is often romantically

described as "empowering the community" to "take ownership" of CBR, is this in fact

the case? The issue of community representation is indeed one of Miles' greatest

concerns, for in his final analysis Miles (1994a) concludes,

> CBR will not belong to the actual *people* of the community, the men and women
> who live along the street or in the village -- it will belong to their
> *representatives* in local government, i.e., the elite which "know best" what is
> good for the people, and which issues the orders. (p. 3, italics in the original)

In summary, CBR's representation of community can be a romantic vision. As

the textual examples illustrate, CBR assumes community is a homogeneous entity

consisting of simple, hard-working and honest folk, well known to one another and

committed to improving the conditions within the community for the betterment of all.

Individual community members are seen to be self-reliant and mutually concerned. The

assumed community is an egalitarian structure where community members extend care

and concern to those in need.

## Romantic Community and IL

CBR is not alone in its romance of community. In official position statements,

and in discussions with elite spokespersons and ordinary people with disabilities, the

143

idea that groups of people and physical places called communities are warm, nurturing and empowering comes through loud and clear. As Cohen (in Everett, 1994) has neatly summarized, IL presents a wholesome picture of the normalcy of community life where "small is beautiful, people are not machines, experts don't know everything, bureaucracies are anti-human, institutions are unnatural and bad, the community is natural and good" (p. 66). Brown (1992) provides another example when he relates an occasion at a disability conference where he and others in attendance shared their disability experience. This was obviously a powerful moment for all concerned. Brown writes:

> We left plenty of time for audience participation -- but it was not enough. Everyone in the audience, it seemed, had a story they wished to share. One of my colleagues on the panel kept commenting that we had to find some way to take down all the stories that were in that room, let alone those that existed outside of it. The excitement of that panel was so vibrant in the air that it almost seemed visible. Clearly many people believed that they had stories that demanded telling. The room was alive with a feeling of community and oneness in a mutual struggle to break through both visible and invisible barriers to a sense of group freedom and appreciation. My belief in our common identity was reinforced. (p. 230)

Similar portrayals of disability and community based disability projects are a feature of other literature attributed to IL. The movement not only creates a picture of the naturalness of community, it also perpetuates the idea that people with disabilities united together are a powerful transformative force. This theme is captured in a poem by Keny Aviles from El Salvador (Driedger, Feika & Girón Batres, 1996, p. 37). Reproduced below, this poem is entitled I Have Been Born Again:

144

I used to live locked up between four walls.
I did not know what it was like to enjoy life.
Then, one day, I had the opportunity of meeting
many people who shared my condition,
or worse.

They were always strong, they always looked ahead,
and never felt defeated.
On the contrary, they wanted to conquer,
show their true worth.

They gave my spirit strength
and taught me that life must be lived
as it manifests itself.
Taught me that we must accept ourselves
no matter what we are like, no matter our suffering.
All that counts is that we feel good about ourselves.
The rest doesn't matter.

In this poem, community life is clearly idealized and contrasted with a life "locked up between four walls." The situation confronting people with disabilities is hence tremendously simplified. Meeting people similar to oneself is surely a positive personal experience. But is it sufficient "to conquer all" as the poem suggests? Perhaps more importantly, is "feeling good about ourselves" really enough to change societal structures that prevent people with disabilities from participating fully in society?

When IL idealizes community, as it does above, a number of serious problems are created. First, while individual persons may feel empowered, there may be an emphasis on collective unity and solidarity which does not actually exist. During interviews for this research, a member of a disabled consumer organization in Winnipeg revealed that he had recently become disabled. When asked about his colleagues' reactions to him as a newly disabled person, he replied as follows:

145

The majority of people with disabilities are very supportive in terms of what you're going through. But there are some people with disabilities who then say to you: "You're not as disabled as I am, so what are you complaining about?" That is a total shock! You just go What? What is happening here?

CL:     So there is this hierarchy?

Yeah! And I had heard about that from people, that there is a hierarchy of disability. But it was the first time I personally experienced it.... I would say this is the most shocking thing I have encountered. More shocking than the actual experience of pain, and not knowing what is going on. Its been that. That's been the most shocking thing. And the reason it may not be shocking for others who experience the same thing as me is because they haven't been involved in a movement where the philosophy has been that people will work together. You expect there is going to be support and then there isn't. In fact, its the total opposite. Its more hurtful than a non-disabled person saying "Oh, it's all in your head." Because you can understand their ignorance. But I can't understand this ignorance. Its very disappointing. Loss of faith, almost. Yeah. Loss of faith in the movement.

While this experience could be explained by various factors, the experience of this individual suggests that IL as a movement may not be as supportive as the official rhetoric suggests, or at least to the degree that some people with disabilities expect. Like anywhere else, there can be competition, vested interests and hierarchical structures that do not always meet the needs of individual disabled people.

It is essential to recognize that people with disabilities seek different things from the IL movement. Some want political action, others want personal support. Paul LeJeune, a former national calibre athlete and longtime international officer and volunteer for CCD states,

Well, I think that social movements are not for everybody.... There are some people who do better in self-help support groups, you know, when you get together and share experiences and its very much at a personal level of sharing

146

and supporting each other.  There are a lot of people who don't want to get involved politically.  This is not a Big P political movement.  But once you start talking to decision-makers it becomes political.

To be fair, the lack of overall collective solidarity within IL may reflect the movement's limited resources.  As Asch (1986) identifies, such limitations can have a significant impact on a small group's ability to affect social change.  Speaking about the American situation specifically, Asch says IL has a "small size and stretched-to-the-limit financial, staff, and volunteer resources.  Although local independent living centers and national organizations of people with disabilities seek to represent the interests of all 36 million, with their diverse medical, mental and psychological conditions and their diverse as well as common problems, they are only backed by a fraction of the constituency they claim" (p. 221).  While the disability movement claims to speak for all people with disabilities, not all people with disabilities identify with IL or have felt their views were adequately represented by the movement.  The issue of gender provides a good example.

Women with disabilities have, at times, found themselves very much at the margins of IL.  Driedger (1996), commenting on the founding of the disability movement internationally, writes,

> Like women's experience in other groups and in society, they tended to be in supporting roles or were often given token positions within the executive.... In Canada, women's issues were not considered serious issues by disabled men in the 1970s and early 1980s.  Only when women brought up "important" issues such as transportation, accessibility or housing were they listened to.  Few women held leadership positions and they often felt patronized and laughed at. (p. 13-14)

147

Problems of exclusion in the movement generally were replicated at the organizational level. Driedger (1996) has also documented the ongoing struggles of women with disabilities to secure stable organizational funding support, including the efforts in Canada to sustain the Disabled Women's Network (DAWN). Even at the international level, there have been many frustrations around gender and representation, including within DPI. Driedger (1996) continues: "At the 1983 DPI World Council Meeting, a resolution calling for more representation of women was not acted upon. In 1984 in Jamaica, women with disabilities met separately at a DPI symposium on development and again asked for equal representation. Again, no action was taken" (p. 17). In 1985 however, a resolution calling for fifty percent representation in DPI decision making finally passed. Women's under representation in the international movement has emerged as a serious issue, although specific measures to improve the situation continue to be supported by the membership overall.

The unequal participation and lack of representation by women in IL internationally is not the only problem obscured by a romantic view of community. Dr. Fatima Shah, a blind disability leader from Pakistan, notes that even when greater levels of women's participation are obtained, other problems of exclusion remain. Recalling the first international conference on visually handicapped women convened in 1975 during the International Women's Year, Shah stated: "For the first time in history, approximately 250 blind women from across the globe gathered at the conference to discuss their own situation and to suggest solutions to their problems. It may be noted here that there were only half a dozen women from the developing

148

world" (DPI, 1992, p. 17). Rather than excluding women generally, the new problem to be confronted was the exclusion of women with disabilities in the South. Despite the inclusive language of community and the concomitant images of nurturance and support, various segments of the disability community continue to feel isolated in IL. A romantic depiction of community however, has only meant that issues like gender representation, North-South representation, and cross-disability representation have been ignored. As Asch (1986) states: "Millions of people with less visible and thus less stigmatized conditions, who can thus avoid the day-to-day indignities and injustices of the more obviously disabled, never develop any consciousness of commonality with them" (p. 221).

IL's celebration of the collective power discovered as a result of shared identity and collective purpose clearly has its benefits. Still, there are sticky problems with a romantic vision of community that are less obvious. For example, a review of IL literature leaves the impression that disability activists in the community were solely responsible for the historical gains of the movement overall. It seems as if the community was the battleground where disability rights were won. However, people who lived in institutions and their professional allies were in some cases very influential in the process that brought disability issues to government attention. Grob (1995) reports that it was hardly the case that disability activists "liberated" people from institutions. There is now widespread consensus that many disabled people were often liberated from terrible conditions in family homes in the community. Other disabled people chose to remain in secure and stable institutional environments, not because they

could not survive on the outside, but because all of their friends were there (Grob, 1995; McLean, 1995; White, 1992). This information is not prominent among IL movement documents. Everett (1994) has examined the community-institution phenomenon in the context of the psychiatric survivor movement in North America and writes as follows:

> It might be argued that reform-directed hospital bed closures, consistent with past deinstitutionalization philosophy, imply that "bad" institutions (besides being more expensive) are more likely to violate rights and abuse patients while "good" communities do not. This supposition is untrue on two levels. First, communities regularly neglect, harass and victimize their more vulnerable members, and further, formal government-sponsored community mental health programs are quite capable of violating rights and abusing their clients. Additionally... the extensive network of community services which is supposed to replace psychiatric institutions are, in themselves, "institutional," although they lack the stone walls of the traditional institution. Thus, the question for consideration is, are we once again preparing to cast wider, stronger, different (and perhaps less visible) nets? (p. 67)

The unfortunate juxtaposition of institution and community perpetuates a hardening of disability categories, or a fixed dichotomy between kinds of services believed good and those which are not. But, a sole focus on the negative features of institutional rehabilitation systematically denies a critical examination of their positive aspects. Some professional services and some institutions have been beneficial to some disabled people. Maintaining an artificial separation between the two, as Hirsch (1995) notes, denies legitimacy to the personal experiences of people who lived their lives in these institutions. Raymond Lang, the former editor of CBR News in London, and now with the School of Development Studies at the University of East Anglia in

150

Norwich, England, has spoken about the complexity of the issue as it pertains to institutionalized education specifically. Lang (1995) asks,

> Should children with disability be educated in special schools, or should they be sent to mainstream schools, to be educated alongside their non-disabled peers? My view is that there is no right or wrong answer.... My personal experience of attending a special school was mixed. On one hand, I received a first class education which enabled me to go on to higher education and later to obtain a professional job. However, between the ages of 5 and 19, my experience was one of living in a totally institutionalised environment. When I left school I did not know how to related to my non-disabled peers, and my social development was somewhat immature. (p. 5)

Other people with disabilities feel strongly that there is a need for well-run rehabilitation institutions providing top quality education and skill training. During a recent CBR conference, Godfrey Ooi from Malaysia passionately argued for services for the blind administered through a complex of institutions *and* community based organizations (Solo CBR Workshop, 1995). Ooi argued that only through institutional support can poor but academically gifted people with disabilities have real career opportunities. It is a complex problem, only heightened by the fact that many of the world's most influential disability activists would not have reached their positions without a comprehensive education provided within an institutional system.

This chapter concludes with one final example of the way in which romantic assumptions about community can impact on disability services. Cocks (1994) argues that a fundamental rethinking of service provision for people with disabilities is required. He proposes a community based disability model where the assumptions of unified, cohesive and participatory community prevail. But these features are

151

romanticized. For example, Cocks states that there must be "a close, personal

knowledge of the people, an appreciation of their fundamental and urgent needs, and a

comprehension of the role of the service in relation to these. It is implicit to this

assumption that the service would be relatively small, the size dependent upon the

service purpose, and of a size which enables key stakeholders to know each other

personally" (p. 41). According to Cocks, services on a small scale that permit face-to-

face contact between people ensures a superior outcome. In the second place, Cocks

insists, ordinary people with disabilities must play a central role in the definition of

services. We read as follows:

> Problems are defined as much as possible so that ordinary people from families,
> neighbourhoods and communities play central roles, rather than requiring large,
> impersonal and systemic interventions. Included as "ordinary people" are those
> who use services. The underpinning assumption here is that the time and
> commitment of ordinary citizens is of great value and necessary for the address
> of human and social problems. (p. 43)

A romantic view of community favours the local, the personal and the familiar --

precisely as Cocks does here. Continuing his description of the ideal community

model, Cocks says naturally-occurring networks must be enhanced, and that resources

for disability must be mobilized and controlled at local levels. What does that mean,

"naturally occurring"? Cocks does not explain. He does say however, that for best

results, services ought to emphasize informality. In addition, he stresses "the value of

participatory processes and empowerment in the address of problems" (p. 43). But

these concepts are not defined either. In short, Cocks' (1994) proposed paradigm of

152

disability services succumbs to a romantic vision. The model assumes both the availability and commitment of family and friends to support people with disabilities. It further assumes that informality and familiarity are clearcut advantages in the delivery of disability services. The proposed model assumes local control will avoid the pitfalls of centralized control, and that participation by ordinary people will provide a superior quality of rehabilitation. While Cocks claims that his model offers distinct advantages to conventional disability service provision, these assertions must be put to the test. Otherwise, all of the features of Cocks' model remain premised upon an uncritical and romantic view of community.

## Summary

This chapter has shown that IL and CBR frame community and institution as opposites. The community is both the physical place and symbolic space beyond the control of institutions. Community living is perceived as normal, and as such, becomes the rightful place for people with disabilities. However, when the institution exists as a reified symbol of all that is oppressive about traditional and professional methods of rehabilitation, community life becomes nothing less than perfection. The dynamic features of real geographical communities and communities of identity, and the actual processes by which these communities are mobilized are left completely unexamined.

Not all people with disabilities belong to IL or are helped by CBR. Western notions of liberation and independence may not work cross-culturally either. It is essential to scrutinize the features of community closely, and be aware of romantic

153

tendencies.  The specific kind of problems generated by romantic community is the topic to which we now turn.

# COMMUNITY AND ITS DISCONTENTS

## Introduction

Community and its Discontents details the processes that relate to CBR and IL implementation. This chapter argues that once community is constructed as geography (CBR) or as identity and belonging (IL), social relationships and processes reliant upon that conceptualization become shaped in specific ways as well.

While the idea of community for IL and CBR differs, it is interesting to note that actual IL and CBR projects often share similar assumptions. For example, both tend to assume community needs will be identified rather spontaneously and unproblematically "by the community." IL and CBR also assume the community is relatively homogeneous and equitable. They do not anticipate conflict or dissent. Selection of disability workers is also expected to be straightforward, and community participation is expected to be generated rather easily. However, the concrete reality of project implementation is often very different, with the problem of community representation being particularly troublesome. Strong leaders from within and beyond the community can and do affect the success of IL and CBR. Since IL and CBR both tend to assume the presence of an ideal form of community, problems in project implementation should not be that surprising.

This chapter proceeds as follows: First, the cross-cultural applicability of IL and CBR ideology is examined. The question addressed here is the extent to which essentially Western ideologies fit the Southern context. The behaviours of

155

contemporary communities in the South with respect to disability project

implementation are investigated next. The question concerning us here is the ability of

so-called communities to support disability initiatives at the local level. In other words,

do these groups have the interest and capacity to provide rehabilitation to people with

disabilities within their jurisdiction? The third task is to examine the persistent

assertion of community as a democratic entity. What evidence is there that this is so?

The theme of democracy underlies another central issue in this chapter, community

representation. The representation issue encompasses questions such as Who counts as

disabled? And Who has the right to speak for the community? The final section of the

chapter analyzes the community representation issue more fully, examining the factors

which facilitate project implementation and those which threaten it.


## The Individual, Autonomy and Independence

While the emergence of IL and CBR must be recognized as having complicated

origins across the globe, it is still fair to characterize them both as predominantly

Western phenomena. As such, they have been tremendously influenced by liberal

notions of autonomy and self-determination derived in the Euro/North American

tradition. The question then, is one of cross-cultural portability. To what extent are

the values and principles emphasized by IL and CBR ideology recognized as such in the

South?

The issue of ideological portability is a significant one and it penetrates much

more deeply into the culture of disability and rehabilitation than mere content or style

156

of program delivery. Research has shown that values such as personal autonomy, individual choice and functional independence, so highly prized in the North, may not be as valued in the South (Gallagher & Subedi, 1992; Ingstad, 1995). Dr. Jayant Lele (1993), who has worked extensively in rural India, has found that "a sense of community as social relationship" may mean quite different things in the North and South. Islam and Wiltshire (1994) report findings that further suggest that the functions and activities of communities are not the same in these two parts of the world. In short, we cannot assume, as IL and CBR often do, that individualism and independence are so significant in the rehabilitation process. Many researchers have consistently argued that complicated social, religious, cultural and political norms and structures are at the core of a complete understanding of disability in the South (Madan, 1987; Nichter, 1986; Rifkin, 1983; Stone, 1986 & 1992; Woelk, 1992). One should expect little meaningful insight into the concept of community without the benefit of this contextual background. Deschesne's (1995, March) recent evaluation of CBR fieldworkers highlights the difficulties related even to CBR training, strongly influenced as it often is by Western rehabilitation experts. The situation Deschesne describes arose during routine CBR activities in Central Java. After interviewing villagers about disability in a region and being told that "they knew of no people with any disability problems," CBR fieldworkers came upon a small but successful business being run by a group of disabled people. When asked, the villagers said they had not identified those people as disabled because of their financial success. In this one region of Java then, it appears that the meaning of disability is closely tied to normal social roles and

157

economic self-sufficiency. Western assumptions about what counts as disabled can therefore be misleading outside that locale. It is against this backdrop, namely the social construction of disability, that IL and CBR project implementation in the South must be understood.

## Problems with Ideological Fit

CBR has a relatively longer history and stronger presence in the South than IL. Organizations of people with disabilities are only beginning to emerge, and at this early stage, the organizations are very fragile and fragmented. In fact, many disabled people in the South are not likely to even realize that a disability movement exists (Armstrong, 1993). When this is the case, the question of cross-cultural applicability of IL principles is somewhat beside the point. The situation of a disabled Indonesian man interviewed for this research is illustrative. This man was injured from a fall while harvesting coconuts near his village of Teluk in Wonosobo District in rural Java. This is an area where CBR services are provided by the Solo CBR Center. Through translation, the man said

> We have no experience with community rehabilitation. I have heard of the Solo CBR Centre but they cannot help me. It is the family responsibility to care for people with disabilities. And there are no finances. We consulted with the *dukun* [religious healers] and used *jamu* [medicinal roots and herbs], but nothing helped. Sometimes, the disabled are a burden to society, even their family. But what can we do? We must bear it.

After the accident, the man's wife became the sole income earner for the family. She

158

cooked food at a street-side *warung* (small food stand) in Teluk. The family had far too

few resources to afford a wheelchair. So, the man used a low wooden cart with

wheels, fabricated by his brother, to get around his home. While he had been

encouraged by CBR cadres to investigate income-generation opportunities, numerous

difficulties including the severity of his physical disability meant there would likely be

little progress in this regard.

For those who are aware of and can avail themselves of rehabilitation programs,

there is a recognition that IL and CBR projects founded on principles of rights and

independence may not be completely culturally relevant. North American consumer

models like IL and rehabilitation models like CBR emphasize individual problem-

solving which may not be adopted in the South where conflicting cultural values of

family and kinship promote protection and caring of disabled people (Geertz, 1960;

Kugelmass, 1990). Ron Chandran-Dudley says,

> You see, when you are in the Indonesian culture and you say independent
> living, it means you are moving away from your extended family background.
> You want to be away from it. You are independent. It has got a connotation of
> contrariness. I am wanting to be a rebel. I want my independence! So just give
> me my share, my property, and I am away!

To be sure, in the West, disabled people have achieved a great deal by emphasizing

human rights and service entitlements. Within the very different socioeconomic context

of the South however, how are rights claims interpreted and are rights what people with

disabilities wish to priorize?

The difficulties with the ideological fit of IL and CBR are well known.

Disability advocates in the South are also well aware of the influence of Western ideas on disability programs and services. Dr. Ajit Dalal, a respected Indian psychologist and CBR researcher says,

> The whole idea of independence, especially in the Asian context, means way more interdependence. Everyone is connected. It is all networks. So the idea of doing it yourself is unusual. So why would we teach it? It is much more usual to teach people how to get people to help you. In fact, you are much more of a community member if you are like that than if you try to do it yourself. So, we try not to actually use that word independence. It really doesn't work.

"Doing it yourself" may not be the normal practice in some Southern contexts. There may be reciprocal roles within the extended family or within a larger social network that IL and CBR project managers ignore to their peril. Furthermore, industrious and entrepreneurial behaviour typically encouraged in the West may not only be unusual but distinctly disadvantageous in the South. They may produce unanticipated consequences for the social structure. For example, interactions within the family and between the families of the disabled and the other organizations or institutions in the community may be altered. Deschesne (1995, March) reports the story of one young Javanese woman with mild polio who volunteered as a CBR cadre in Indonesia. At first, the *lurah* (village head) and the *kasepuhan* (the highly respected but informal group of advisors to the village head) did not take her involvement seriously. The young woman felt that because of her disability, no real contribution was expected. In fact, when she went to public places like the local *posyandu* (village health post) and the *puskesmas* (district health office) to offer her expertise to the government health officials who train

160

community health nurses, they thought she was there to beg. While a naive reading of this situation might suggest that attitudes toward disabled people are negative, there are other potential explanations. Java is traditionally a patriarchal and paternalistic society (Anderson, 1972; Stoler, 1977). Especially in rural settings, respect for elders is also taken very seriously (Rudkin, 1994). This CBR cadre was young and female, not only disabled. She was also very open and assertive in her efforts to increase public awareness of disability. In contrast to her behaviour, it is obedience, self-control and poise that are viewed as ideal virtues in traditional Javanese culture (Koentjaraningrat, 1985). The Javanese also place high value on harmonious integration with others. Indonesians have learned that promoting harmony among differences is necessary for survival. Hence, traditional Indonesian life has the outward appearance of peacefulness; hostility, aggression, and conflict are rarely displayed publicly, no matter what the circumstances (Anderson, 1972; Geertz, 1961; Geertz, 1960). The unacceptability of challenging elders and persons of higher social rank is also deeply ingrained in the Javanese normative system. Great respect and deference must still be shown to males, the elderly and people holding public office. Disability projects heavily influenced by the North American disability movement and Western, mostly professionally initiated CBR, may at times and in some ways conflict with these traditional norms.

The use of the language of the North American disability movement has also been a problem in the South, with the words independence and empowerment creating particular difficulty. The movement's emphasis on a rights approach is especially

problematic in countries where human rights abuses are not infrequent among the able-bodied population. Justine Kiwanuka was born in Uganda and lived in Kenya for five years before emigrating to Canada in 1988. She is currently employed by DPI in Winnipeg. Commenting on her personal experience as a young disabled women in the South, Kiwanuka says,

> As soon as you say independence, they say, "What are you people going to do"? There is fear. If people with disabilities don't have the skills or the education or the assets in place, and they do not, then the government wonders whether people with disabilities will be a burden. And then, the government will have to do something for them or shut them up. They are afraid of the potential power of those people. If only they could see how it isn't so bad. People with disabilities are not asking for anything extraordinary. It is just the rights they deserve.

In some countries, governments fear the rights assertions of IL. Not infrequently, DPOs in the South have had to alter their language and temper the militancy of their assertions. Within the Indonesian context for example, DPI representatives must be very cautious in their lobbying efforts with politicians and health bureaucrats. Western IL and CBR experts often have limited understanding of the sensitivity of these matters and the delicate diplomatic manoeuvres which must be undertaken by disability advocates to enhance, and not accidentally erode, efforts to establish more and better treatment for people with disabilities. The RI Conference in Jakarta was an occasion for heated debate on the subject of the legitimacy of a Western-style disability movement in the South. An experienced CBR project manager became quite angered by the naiveté of an American activist in attendance and her recommendations around

162

the use of rights language in disability advocacy efforts. Convinced that an emphasis on rights can backfire, and that the Euro/North American disability movement can learn from their own mistakes before giving advice to disabled people in the South, the CBR manager stated,

> When XXX was talking in Jakarta, I thought, that's not going to work! It's not going to wash here. No way! People in this room do not understand. They do not connect. You can't. You are being as much of a colonialist as anyone if you bring North American ideas, bring them over here. You can get shot for saying things like that in this country! So I think these IL people are naive. At best, they can teach people simple advocacy skills. But they have to be translated. I don't think the Europeans and the Swedes can even relate to what is needed here either. Even if people born in more democratic countries like Bangladesh or India, even if they take on some of the same advocacy strategies, I am not sure that they are effective. I think everyone has to think about how advocacy and rights work in their system. I think the IL movement in developing countries has to be really careful in how they do it.

Rights language is not always appropriate in the South. In addition, as these remarks highlight, historical attempts to transfer models of community based disability service provision from the North to the South have often failed (Ingstad & Whyte, 1995). The transfer of disability ideology and service delivery models is clearly not problem-free.

Finally, and in addition to the problems associated with an ideology of rights and independence, people with disabilities in the South appear to have some difficulty identifying with and accepting IL's emphasis on collective identity and self-esteem. This brings to the surface underlying tensions between individual autonomy assertions and IL's claim of collective identity. Where is the dividing line between personal experience and the movement's unity of mission? This tension is all the more acute in

163

Southern countries where all such issues take a backseat to the more pragmatic

problems related to obtaining assistive devices and specialized rehabilitation equipment,

for example. Without basic aids for everyday living, discussions about collective

advocacy become largely moot. A blind Indian women present at the RI Conference

took issue with many statements made by a Canadian disability advocate. The Indian

woman said,

> I must tell you that the greatest support that disabled people have had for their
> aspirations for independent living has been assistive devices. When we had to
> depend on the individual to carry us from one place to another, or to sit down
> and read to us, you are dependent upon another human being. That deprives
> you of your human independence. But if you are able to wheel yourself around
> ... that gives you an amazing extent of independence on your own terms.

In this statement, the legitimacy of an IL movement that emphasizes primarily rights

and social advocacy. In the South, it has often been the case that medical technology,

not words, has been the most helpful export. Unlike the situation in the North, where

contact with professionals and professional interventions are often thought oppressive,

professional interest in disability in the South is often welcomed. Where few other

mechanisms exist for provision of rehabilitation equipment and services, any project

that offers them gains significant notoriety, and usually commitment too (Lysack &

Kaufert, 1996). People with disabilities in the South are not looking inward examining

their feelings, and they are not rejecting the advances of medical professionals. In

previous research conducted with women who volunteer as CBR cadres for example, it

is clear that more, not less professional assistance would be appreciated. Walktu, a

CBR cadre in Sojokerto village, summed up her daily obligations as follows:

> Time is our biggest problem. There are too many other activities. I rise at 4:30 in the morning everyday to cook, clean, get my children ready for school, do washing at the river, cook more, and do mending until 4:00 in the afternoon. Then, after supper, I clean up. Its dark, and then I still cook some more. (Lysack, 1992, p. 95)

CBR cadres are occupied with food preparation, cleaning, care of children and elderly family members, and often times agricultural work in the family fields. As a result, Walktu's concern is not with collective identity, it is with finding ways to help disabled children in the village where she lives. Many countries in the South completely lack the health and social safety net taken for granted in North America. At their early stages then, disability projects must be focussed on basic needs. Laura Krefting states,

> If I have a kid with a cleft palate, I don't want to see any activist! I want to see a surgeon. Without medical professionals, we are lost. We underestimate how much medical rehabilitation and technical skill is still needed to get people interested in disability programs in the community. Philosophically we think and say, "Oh no, this is a community development project. We should give education -- stuff like that." But the fact is people aren't interested in that until you can show them that you can do some things. They want to see the goods.

Krefting is not implying that advocacy issues are unimportant. She is emphatic about the timing and emphasis of intervention priorities though. In her experience, which is considerable, people with disabilities will not participate in either IL or CBR if it does not quickly and directly improve their lives.

In summary, the transfer of IL and CBR language and service delivery from the North to the South has been the source of numerous difficulties. People with

165

disabilities have not always understood the rights rhetoric attached to IL and CBR,

developed as they were in the North. Instead, they have demanded visible

improvements in the quality of their lives via corrective surgeries and specialized

equipment. The language of independence has also been significantly altered by

disability advocates in the South, in part because independence has been interpreted to

mean isolation from family, the greatest and sometimes only source of support for

people with disabilities. Significant adaptation of both IL and CBR ideology is

therefore necessary for community based disability initiatives in the South to have a

favourable impact.


## Communities of Communion and Cooperation?

The romantic view of community that permeates IL and CBR ideology is the

same one that permeates the process of project implementation. When the idea of

community held is a sentimental one however, the community may take on attributes it

does not actually possess. While IL and CBR proponents are beginning to recognize

the inherent diversity of communities (Solo Workshop, 1995), there remains for both a

tendency to overestimate the extent to which people agree on the importance of

disability and their willingness to fully cooperate with each other to enhance the quality

of life for people with disabilities. Mario Abaygar has observed first-hand the

difficulties encountered in establishing disability programs. Mario, who has polio,

represents KAMPI (the National Federation of Disabled Peoples) in the Philippines.

Recounting a recent experience, this articulate young leader stated,

166

> I was part of an initiators training seminar for a community-based disability project sponsored by XXX in Quezon City. There was big enthusiasm at the start! But, we had no guidance and no follow-up. There was insufficient support to carry out the actions recommended at the seminar. When we got home, we didn't really know where to start. And the leaders? The leaders of XXX are self-interested. They do not care too much for the people. They wanted to attend meetings, to travel. And not only that. They were insufficiently sensitive to the needs of the people.

In part, the implementation process was a struggle because those providing the training did not provide what was expected. In addition however, the issue of who ultimately becomes responsible for the continuation of a disability project at the local level, and the extent that they can ensure successful rehabilitation outcomes, is also highlighted. Sujata Parekh of the Spastics Society of Eastern India in Calcutta discussed this issue with Mario Abaygar, contributing an experience of her own to the general debate. She said,

> There was a family we knew on the outskirts of Calcutta with a large family. The youngest daughter was 9 months of age. The older girl was 8 years. She had cerebral palsy at birth. She attended our CBR Center weekly for about 4 months. She learnt to feed herself and how to do some handicrafts. The father was a daily labourer. So, when the mother took the older child to the Center, the father forfeited his daily wage to care for the baby. We gave them free CBR booklets in Bengali. There was some follow-up and it was useful. After some time, the family made arrangements for the girl to travel to the Center with another family who had hired a driver and cart once a week. Some time later though, she stopped attending. And we didn't know why. Only much later, through another teacher I know, did we find out that the driver was taking their money on some occasions. The family was most angry, once they knew. And of course the girl could not speak very well. But what could they do? They had no other way.

Parekh's story is not unusual. Similar reports were shared at the Pre-Conference Workshop of CBR in Solo (Solo CBR Workshop, 1995). Another example, confirms

that a myriad of problems confront such efforts. Recently returned from a volunteer

assignment in the Ivory Coast, Paul LeJeune has considerable experience as a CCD

consultant on small-scale disability project implementation. LeJeune states,

> People are people everywhere. They want the best they can get from anywhere.
> Some want hand-outs from religious groups and charities. Others work hard.
> Still others, have no options and no choices. There is no such thing as disability
> rights and independent living for them! My friend on the Ivory Coast told me
> "We all have rights, but that doesn't mean anything. It's still our families who
> look after us." They say everything is for sale in Africa. For disabled people
> in Africa though, it's income-generation and power they need. For sure!
> Everyone wants to improve their life! People with disabilities must develop
> some way to get money to survive. They don't think too much past that. So
> what do they do? They do what they have to do to live.

These three examples from the field in the Philippines, India and Africa illustrate some

of the practical problems associated with community based disability project

implementation. In short, the central problem is that community life is not as ideal or

traditional as many project planners expect. The community is not just waiting to

participate in IL and CBR. Even the most seasoned project managers in the South can

be surprised at the complexity of project implementation. The experience of the Solo

CBR Center is a case in point.

The YPAC CBR Center is a well-established indigenous organization in Central

Java. A major organizational focus is training CBR volunteers to identify young

disabled children who are regularly weighed at the local *posyandu*. Children thought to

have a disability are then referred to the *puskesmas* where a government health nurse

and sometimes a physician diagnoses their problem. The second major focus of the

Center is to promote more positive attitudes towards people with disabilities.

Sometimes this task involves public education. The following "failure" story was

related by Douglas Krefting, the manager in charge of CBR operations during that time.

His story is paraphrased below:

> The Solo CBR Centre was involved in developing an educational video for village distribution. We decided to work to incorporate positive disability messages into traditional Javanese stories. The video therefore took the shape of recorded puppet theatre plays. The production cost was US $10,000 which was a tremendous investment for us. But, we were absolutely shocked to discover the villagers were uninterested! Everyone liked to watch videos. But they did not want to see traditional Javanese stories. They wanted something new, something different, something interesting. Like the dramas they see on TV. They told us they wanted to see something modern, Western and entertaining -- not old stories. The moral for us is to listen to the local people, including our CBR fieldworkers, which we had, but obviously not closely enough! Now we are using much more participatory techniques. It is a real lesson, to listen.

The staff at the Solo CBR Center were very knowledgeable, and yet they miscalculated

the villagers' preferences with respect to disability education. Once again, it appears

that traditional community values may have been assumed. Still, the issue is complex.

Rural Indonesia is undergoing rapid sociocultural transformation like many other

countries in Southeast Asia. Villagers in the countryside are watching CNN News and

old American television programs such as Dallas, Gilligan's Island, and the Edge of

Night -- dubbed in Bahasa Indonesian, the nation's official language. These same

villagers may not have ever seen a wheelchair however (except on television), and

many still believe disabilities are caused by witchcraft (Koentjaraningrat, 1985;

Woodward, 1985). Access to media and new information may be dramatically altering

sociocultural norms and values, just as this incident reveals.

A careful examination of the international community development literature shows community is a diverse and often tumultuous place (Kothari & Mehta, 1990; Stone. 1992). Specific analyses of the disability context in the South suggests a similar thing (Lysack, 1996a). Those involved with disability projects on a daily basis are also quick to point out that while traditional views of community may be quite mistaken, they nonetheless continue to persist. Leonard Williams, an experienced CBR project manager in the Solomon Islands, argues that the social and cultural changes occurring in families in the South today are real, and that they are having a major impact on the idea of community. For example, Williams says people who used to provide assistance for village improvements now have serious reservations about the time and financial implications. For CBR and IL projects, heavily reliant upon unpaid labour as they are, this poses a major problem.

> One of the central concepts behind CBR is that people give their time, labour and resources freely. Our traditional way of life has revolved around support from the extended family and clan--the *wantalk* system--with people making a living from fishing and harvesting coconuts and other local produce. Today, on most islands, lifestyles have become more westernized and people expect to be paid for their work, even if it benefits the community as a whole (such as clean water supply, school or clinic). Occasionally communities will give voluntary service, but this is generally a one-of thing and cannot be expected for long-term projects... The traditional *wantalk* system, whereby families care and provide for their disabled members, has gradually been eroded, and families now expect some payment for their involvement in CBR. This barrier hinders the effectiveness of CBR in local communities. (Williams, 1996, p. 5)

Just as the traditional *wantalk* system in the Solomon Islands is being eroded with time

170

and Western influence, so too is the Indonesian custom of mutual aid or *gotong-royong* (Koentjaraningrat, 1985). *Gotong-royong* is a form of reciprocal cooperation, a tradition of maintaining good relations with one's neighbours. To ignore the custom risks being identified as a bad person who community members would be reluctant to help in future. In Central Java, numerous kinds of communal projects are accomplished by *gotong-royong* including the offering of personal assistance to less fortunate neighbours, most often in the form of additional food and labour. Rendering assistance in times of sickness, accident or death are also common. There is firm evidence to suggest that such social customs provide a favourable basis for CBR (Kalangie, 1995, January; Sutopo, 1993; Deschesne, 1995, March). In Java in particular, population pressures have escalated over the last several decades, and it is not unreasonable to assume these pressures will have a negative influence upon traditions of collective responsibility and communal allegiance. While the language and imagery of steadfast commitment to village welfare continues to characterize the ideology of IL and CBR, there appears to be a persistent gap between the ideal of community participation and what actually transpires in rural villages in the South.

## Community as Democracy?

As the previous sections of this chapter illustrate, both CBR and IL have made some mistakes in their efforts to transfer their ideology from North to South. Some of these mistakes are related to unacknowledged and unarticulated assumptions about the relationship between community participation and democracy.

171

In theory, community participation is believed to improve the overall quality of disability services, because the people who know about disability are intimately involved its planning and implementation. Experienced commentators believe CBR and IL have not succeeded in encouraging broad democratic partnerships however (Miles, 1994b). This research offers an explanation why the ideal of participation is not achieved. Community members may not have genuine decision-making control over issues that affect their lives. Community participation can be controlled by powerful individuals who do not have the best interests of disabled people, or even the best interests of an entire village in mind. Desires for personal gain or alternative organizational or political goals may also alter disability priorities. Thus, what is best for the community most certainly depends first, on what the community is defined to be, and after that, upon what community stakeholders decide best means.

Billy Barnaart is a physiotherapist and CBR resource person with KHEMARA (A Cambodian NGO for the Advancement of Women). Barnaart is an outspoken critic of disability projects called community based that are actually controlled by professionals or government officials. Barnaart has long been concerned that the needs and ideas of disabled people themselves are inappropriately filtered by official representatives and many levels of organizational hierarchy and interagency bureaucracy. The filter Barnaart refers to is the filter of two-way communication, that is, bottom-up needs articulation and top-down imposition of organizational interpretations. These structures of power are exceedingly complex. Villages representatives carry their concerns about disability to higher administrative and

political levels. Interested health professionals, local political leaders and international funding agencies with a stake in disability projects in the South may also be involved. Hearing the voice of people with disabilities within this web of interests is a major problem. The fundamental issue is this: Who has the power to define disability problems and determine priorities for remediation? This is the issue of community representation.

Community representation poses difficulties for the implementation of IL and CBR at multiple levels. At the ideological level, these approaches ask people with disabilities and their communities to take ownership of their problems and seek appropriate solutions. Disability projects are not controlled by ordinary disabled people however. They are controlled by a select group of disability leaders. It is these leaders who bring forward their constituency's concerns. At another level, it is the national and local socioeconomic climate that will affect disability projects, and at both levels, there may be expected and unanticipated impediments to "the will of the people". In countries such as Indonesia, expressions of community face the additional challenge of overcoming strict political control. Within such a climate, community development initiatives are unavoidably altered. To survive, project managers must be sensitive to shifts in both political direction and public mood. But to return to our central concern of community representation, the central issue is that identification of community needs and means to address them are a far from self-evident process. A University of Jakarta student interviewed for this research provides an example.

The student was waiting for the Indonesian Ministry of Social Affairs to review

173

his application to the pharmacy faculty. This Ministry is responsible for screening applicants with disabilities. (The student used two crutches to walk.) Despite his close acquaintance with the national education bureaucracy, he was dismayed with the inefficiencies and corruption he saw in the Ministry. He was also upset that the Indonesian office of DPI could not seem to exert any useful influence in this regard. He was also critical of DPI's close ties to the Indonesian government and ruling Soeharto family, suggesting this organization had little genuine concern for ordinary disabled citizens. He further complained that disability organizations continue to perpetuate workshop-style environments under the guise of community programming when there is a pressing urgency for real income-generating projects. He added that workshops do nothing to improve Indonesian's view of people with disabilities, they only help to raise funds internationally. In his mind, becoming a pharmacist and demonstrating financial success would do more to change attitudes than anything else. He said,

> Disabled people in developing countries should not be objects of pity. That's what some people think! And you know, some people perpetuate the mythology of running a good IL-type disability project just to increase the donations from North America. And then, they do what they want with it afterwards. You know, we need real income generation, not basket weaving. And not goodwill. If we are such good workers at basket weaving and needlepoint, why aren't we soldering components on motherboards?

Community based disability projects ought to reflect local needs and include genuine community participation. But as this student identifies, projects may not achieve the ideal. Sometimes the barrier to community participation rests with internal

174

organizational issues, and at other times, on external factors. In any event,

continuation of so-called community programs when the community does not see it that

way puts project sustainability at risk. Democratic participation does not develop

without great effort. It will not spontaneously emerge simply by calling programs

community based. A closer examination of community participation and community

representation is thus in order.


## Leaders and Elite Control

Community for CBR and IL is more than just people with disabilities. There

are a diverse number of other stakeholders in the community. Their influence may be

so substantial that even the movement's most elite leaders may lack the necessary

power to ensure the priority of disability issues -- either at the local level or at the level

of national social policy. This presents advocates from both IL and CBR with a

significant dilemma. How can they improve the situation for people with disabilities,

and at the same time, allow small-scale disability initiatives to develop via the

community development or bottom-up approach? In other words, how do dedicated

leaders assert the importance of disability beyond the boundaries of the movement

without dominating the local scene and controlling its direction? If IL is truly a social

movement, then matters of control and representation are central. Similarly, if CBR is

committed to a community development approach, then the voices of all community

members must be heard. So, are the external and internal goals of the disability

movement antithetical? A partial answer to this question rests with the individuals who

175

are the primary leaders and spokespersons of IL and CBR.

The people with disabilities who have become international IL and CBR spokespersons are a rather special lot (Lysack & Kaufert, 1994a). Most come from wealthy families who have been able to provide their disabled offspring with a strong formal education and provide the financial resources necessary to obtain the highest quality assistive technology on the market. It is also clear that disabled elites in the South have many more privileges than those they represent. DPI Singapore publishes a magazine called the Integrator for the interest of its national membership. The cover story of the April-June 1995 issue describes a recent meeting of Mr. Koesbiono Sarmanhadi, President of DPI Indonesia, and several other disability leaders in Southeast Asia. Mr. Koesbiono became a wheelchair-user in 1959 when he lost the use of his legs in a traffic accident. He was a high school student at the time. Despite his disability, he pursued his studies and became a Notary Lawyer. The article states, "He has excelled himself in his private practise and is also a prominent person in Indonesia, providing legal advice to many prominent people" (p. 1). The Integrator article also provides some insight into international meetings. The story was illustrated with photographs of smiling participants enjoying each other's company at the Checkers Cafe at the Hilton Hotel in downtown Singapore. Apparently, the meetings were rather pleasant. We read as follows:

> ... with the rattling of cups and saucers as members of the team tried to serve tea to each other, the hissing sound from the process of making Cappuccino from a nearby counter, and piped-in soft music, formed a cosy and homely environment.

Those in attendance at such meetings are not typical disabled people. Elite

representatives enjoy a privileged lifestyle, dramatically different from the rank and

file. Elite leaders also gain a certain level of prestige through their affiliation with

international CBR and IL. In countries where organizations have close governmental

affiliations, the status and power of these individuals can be significant. Mr.

Koesbiono of DPI, for example, is also a relative of the Soeharto family in Indonesia.

His political connections are extensive. While these relationships may present

opportunities to positively influence disability policy, Mr. Koesbiono may also be

forced to chose between maintaining these relationships, and the personal benefits that

flow from them, and lobbying for increased rights and services for disabled people. A

DPI representative from the Asia-Pacific who wished to remain anonymous stated,

> DPI representatives in developing countries are not risk-takers. They come
> from socially elite, high-income families and they get together once or twice
> annually, often at a large international conference. They are not connected with
> ordinary disabled consumers. They have never known their concerns.

The representativeness of elite leaders can always be called into question. In a strongly

worded article entitled CBR: Conference-Based or Community-Based, India

correspondent Selim (1995) criticizes CBR elites and their distance from the real

experience of people with disabilities. As with IL, the concern is that CBR experts

enjoy special benefits that ordinary disabled people do not. In the article, Selim writes,

> Organized by Action-Aid India's Disability Division and Canada's International
> Centre for the Advancement of Community Based Rehabilitation, they grappled
> with "Research and Evaluation of CBR" at a luxury hotel and burnt out a

177

photocopier supplying 120 participants with papers. Senior federal officers and heads of India's national rehabilitation institutions attended as well as international CBR "big guns." (p. 22)

Selim is not only concerned about wasted resources, however. He is asking whether elites representatives understand the daily problems confronting ordinary disabled people. New social movements may always be "thin red lines," and disability may be a case in point. The movement may be trapped in the dilemma of needing to assert its claims without adequate evaluation of its representation.

## Gender, Class and Ethnic Representation

While some elites within IL and CBR lead quite privileged lives in comparison to their non-elite counterparts, more frequently it is the case that disability leaders have limited visibility and limited power in their own countries, in turn, a product of the general invisibility characteristic of disabled people more generally. In both cases however, a leader's ability to carry the needs and wishes of the majority to the places where decisions are made is severely compromised. Furthermore, while elite representation is not necessarily bad, it does contradict the official disability movement rhetoric of equal participation and equality, at least to some degree. A Kenyan CBR spokesperson notes,

> I have definite concerns around not reaching the underclass; definite concerns around not reaching the illiterate; definite concerns around women and representation. The movement is just not effective if it does not incorporate their wishes and methods.

178

Another criticism of IL and CBR leadership historically is that it has been very male

dominated. This sometimes means that the needs of women with disabilities are not

well identified or addressed. Justine Kiwanuka from DPI Canada says,

> When I was in Sri Lanka, there was a bit of a problem. I kept on listening to
> my counterparts, and sharing and talking about women and disabilities in the
> country. I wanted to get the women's perspective, but the men kept on telling
> me what they think women feel. But at one point I said, "Can they tell you
> what they feel, really?" I didn't want to be so very assertive, you know,
> because of their culture. It was a sensitive thing. But the women knew what
> they wanted. And here are the leaders, the men, saying they knew what women
> wanted without ever asking them. So, I just felt, could we just please ask them.

These examples are not meant to imply that elite representation issues only pose

problems for disability advocates in the South. On the contrary. Similar challenges

continue to exist in the North, and they relate to issues of gender, class and ethnicity.

For example, in North America, the historical leaders of the IL movement were young

spinal cord injured men in wheelchairs. The original leaders were not women, or

people with mental disabilities. While cross-disability representation and a more

prominent position for women in leadership are increasing, reaching ethnic minorities

with disabilities continues to present a problem. Commenting on the Canadian

situation, Paul LeJeune says,

> Ethnic participation? There isn't much. And there is very little participation of
> non-white people. Very little participation by people of colour in the IL
> movement. There is some representation of Aboriginal peoples but it is not
> very large either. So there is lots of work to be done in terms of representing
> all Canadians with disabilities, and also working on services for all Canadians.

179

Asked about other divisions between the purported constituency of IL and its leaders,
LeJeune continues,

> Well, of course there are class distinctions! That goes without saying. How
> else would someone get the job? Who else knows how to do this if you have
> never gone to school or had any other form of employment. How many get the
> chance to do that, especially in developing countries? You know? And it's true
> even here too. Even here.

Lori Ross at the ILRC in Winnipeg confirms that a hierarchy of disability also exists

within the general membership of the IL movement. Ross says "The hierarchy of

disability has put wheelchair users at the top, right. That's very interesting. In other

countries, they put blind people at the top. It all depends on what the disability politics

are. And so, I think that people with hidden disabilities are the bottom of the ladder."

Morris (1991) agrees that a hierarchy of power exists within IL, a hierarchy that places

elite wheelchair athletes at the top and women with disabilities, the frail elderly, the

mentally disabled, and disabled persons with significant additional medical problems at

the bottom. This hierarchy also persists in the South. Karen Ngai, a Lecturer in the

Division of Social Studies at the City University of Hong Kong, is also disabled and a

dedicated disability advocate. She says,

> You know, when I was working in Sri Lanka, I noticed many things. For
> instance, you know blind people have many opportunities that are not applied to
> the physically disabled. You know? They have scholarships, they have job
> opportunities, that do not come to others. Maybe it's because of history,
> because the World Blind Union has been around for a very long time.
> Secondly, I think in that part of the world, and maybe all over, the government
> gives more to them too, than to other disability organizations. It's the same in
> India. They have funds available, they have schools. I don't want to use the

word sympathetic -- that people are more sympathetic to blind people. I don't know. Maybe it's the same for people with mental disabilities too.

Unfortunately, it is those disabled people at the bottom of the hierarchy who have the least knowledge and least power to negotiate the complex terrain of medical and social welfare systems. Ultimately, this means that those most in need are those least likely to procure services. Hence many disabled persons, due to conditions largely beyond their control, are systematically isolated from the benefits of rehabilitation and social services, perhaps even from the so-called social movement of disabled people itself.

While the idea of privileged members and elite leaders may run counter to the prevailing IL and CBR rhetoric about community participation, there is mounting evidence to suggest that in some countries, powerful elites may be precisely what is needed to persuade governments to attend to matters of disability (Lysack & Kaufert, 1994a). For example, in Indonesia, the Indonesian Medical Association has played an integral role in assisting NGOs to convince local and national health bureaucracies of the value of disability projects (Sutopo, 1993). Building on their prominent position in the national health system and society more broadly, physicians can influence health policy. From the point of view of emerging DPOs however, IL and CBR's aim of listening to and responding to the felt-needs of communities becomes largely empty rhetoric if medical professionals make all the important decisions about policy and resources. Because professionals actually do confer much needed prestige on disability projects in many countries in the South, the way forward is all the more complex. Building a participatory and democratic disability initiative depends not only on local

181

factors, it is reliant upon national and international factors as well.

The problem of ensuring that the agenda of ordinary disabled people is addressed, whether at the village or global level, is a significant one. Shahidul Haque, the Executive Director of Social Assistance and Rehabilitation for the Physically Vulnerable in Bangladesh was interviewed for this research. Haque, himself a disabled war veteran, reported with some sadness that "the smartest disabled consumers become elite representatives." Mr. Haque felt that once "good people" become elite representatives they "lose touch with the grassroots." Haque continues,

> Pumping more money into the international jet set of DPI is not the answer. Independent Living organizations need funding to support disabled peoples organizations (DPOs) in the developing countries. Can I find money to develop a regional plan? No. All of the major aid organizations will fund me but they won't fund a DPO. Now that's not right. Don't come over here with IL and CBR and everything else. Come here and work with the DPOs and let them grow into what they want to grow into. That's all that DPOs in developed countries want. To grow into what they want to be. Provide them with the opportunity! Get that money and lobby for that money, but let the local DPOs control it themselves.

Unfortunately, money to support disability projects is in critically short supply. Before DPOs can begin to control funds then, they must first find some. An ally of the disability movement in the Philippines, Veronica Mendoza, is a CBR Program Manager in an urban setting near the slums of Manilla. She is very concerned that even the amount of funds major disability organizations possess cannot possibly address the overwhelming poverty and disadvantage faced by people with disabilities. Mendoza states,

182

> The amount of funds for disability worldwide is woefully inadequate. It is less than a drop in the bucket. We really feel sometimes that the world does not care a bit. We try, but it is never enough. Sometimes, you don't believe people care. We desperately want to know how others are coping and what else can be done. But it is not very much. And we get tired and despair.

Other activists within the international disability movement have similar feelings, although some are more angry than Mendoza. These individuals criticize IL and CBR for continuing to export "disability experts" from the North to "fix" disability in the South. They also condemn governments for placing disability so low on the list of national priorities (Solo CBR Workshop, 1995). Dr. Manik Shahani, a physician at the Seth G.S. Medical College in Bombay and longstanding disability advocate says,

> Both India and the United States build jet fighters. You knew that, didn't you? And so, they have billions and billions of dollars to spend, if they want to. Are these countries in a fiscal bind? I don't think so. Only when it comes to matters of disability and the like. It is not so very popular with some, you know.

In another example, one longtime member of CCD in Ontario has seen first hand how disability projects in the South are supported by the disability movement in the North. She is concerned that experts in the North define and control far too many aspects of project implementation. She also believes IL has no clear advantage over CBR in this regard. She states,

> Because there are organizations of persons with disability in developing countries that have organized successfully, perhaps it is those colleagues who have the most relevant knowledge base to share. If there is any kick starting, perhaps it should be from like people in like situations.

Diane Driedger, author of *The Last Civil Rights Movement* and longtime disability

advocate recently returned from assignment in Trinidad adds,

> IL can be just a top-down as CBR. IL is trying to expand into developing
> countries before getting its own house in order. The divisions in Canada are
> growing between people with disabilities with money and those without, for
> example. Yes they are. That should be fixed first before going over there. IL
> isn't wrong, of course. But it shouldn't just parachute in there.

One final example illustrates how the definition of the disability movement relies upon

elite conferences where a small number of prominent disabled individuals represent the

majority. This example illustrates the vast resource gap between some elite disability

leaders and medical professionals and ordinary people with disabilities. The enormity

of the financial disparity is a cause of great concern to DPOs and NGOs in the South as

well as to many elite leaders in IL and CBR.


## The Resource Gap

During the course of this research, international experts in IL and CBR attended

the Asia-Pacific RI Conference in Jakarta. The Conference registration fee was US

$300 and accommodation was US $90 per night, not including travel costs. Obviously,

these costs are overwhelmingly prohibitive to ordinary people with disabilities in the

South. Once again, Indonesia serves as an example. In Wonosobo District in rural

Central Java, the average per capita income in 1992 was approximately Rupiah 30,000

per month, or about US $15 per month (Lysack, 1992). Even the most wealthy

villagers in the District could not afford to attend a Conference such as this. One of the

184

Conference participants, Mr. Moul Chhorn from Cambodia, reported the costs associated with attendance were far beyond his personal means. Even as the Director of Kien Khleang Rehabilitation Center in Phnom Penh, Chhorn's monthly salary was only equivalent to US $20. While a few participants were sponsored by RI or by funds from their home governments, the majority are invited to international conferences under the sponsorship of prominent NGOs, large rehabilitation organizations in the West, or the rehabilitation branches of international organizations such as the WHO, the ILO and the UN. Without exception, the people with disabilities who attended the Pre-Conference Workshop on CBR in Solo, would not have been able to attend without these funds. There would not have been a single person with a disability at the most critical workshop on CBR in the world in 1995.

Early in the evening on the day prior to the official commencement of the RI Conference, a small group of disabled people met informally to discuss the Conference fees. Shahidul Haque from Bangladesh decided to join Moul Chhorn, Billy Barnaart and Yi Veasna from Cambodia and three other individuals in pursuit of a cheaper hotel and shared accommodations. With some creative bookkeeping, they were able to capitalize on their full individual reimbursements, pocketing the difference. They knew their sponsors would hardly approve, but this was not a deterrent. In fact, Moul Chhorn stated his most pressing aim during conferences such as this one was "to bring home more funds than I left with." In broken English he told the researcher he intended to pay his daughter's annual school fees with some of the money and save the rest for a motorcycle, a purchase otherwise impossible for several months.

This incident highlights the resource gap between North and South. But it also highlights the issue of personal self-sufficiency and individual mobility of disabled elites versus the overall mobility for the movement of disabled people in the South. The circumstances faced by Haque, Chhorn and the others provide evidence that so-called disability elites actually lack substantial personal resources. It is only their official status that conveys access to external resources. A naive reading of elite representation within IL and CBR obscures such issues. A naive view of elite representation ignores complex issues of power, politics and the economy. These are the very topics that must be critically examined in order to hold out any promise for a comprehensive understanding of disability in the South.

## Disability and Community Priorities

Community based disability projects are delivered at the local level within a broader development context. Disability therefore competes with other health issues for priority, and also with agriculture, the environment and business. There is always a danger therefore that disability will not be recognized as the most pressing concern. The Final Report of the CBR Experts Workshop in Solo confirms this. The Report states that in many Southern countries, disability ranks well after food security, shelter, education and income-generation on both personal and community agendas (Solo CBR Workshop, 1995). The low priority of disability is a complex phenomenon however, inextricably tied to other factors. Program materials typically associated with community based IL and CBR acknowledge these important factors only infrequently.

186

First, the low priority of disability can to some extent be accounted for by the stigma attached to disability. Negative attitudes, lack of education, and other historical biases within society have been shown to prevent people with disabilities from holding substantial political power (Balcazar, Mathews, Francisco, Fawcett & Seekins, 1994). Second, there is always a relatively small number of disabled people in any defined locality. In contrast to the Women's Movement, for example, the size of the disability movement is exceedingly small, and their geographic dispersion results in a lack of a critical mass of disablement necessary for effective lobbying. A closely related problem is that care of people with disabilities is often not thought of as a community concern. Disability issues are further prevented from assuming centre stage because of the near absence of communication infrastructures and networking mechanisms. Disability may be considered a private affair, primarily a family matter. Diane Driedger suggests,

> Disability is not the same as the Women's Movement or the Black Civil Rights
> Movement because they were in the thousands, or the millions! You know?
> When someone has a disability in a developing country, and in many ways here
> too, it is only their family which is really concerned. Who really thinks about
> it, disability, until it happens to them?

The second major difficulty with respect to generating community interest is that disability projects, particularly CBR projects, often emphasize prevention, the argument being that professional rehabilitation is far more difficult and expensive than preventing disability in the first place. In practice however, prevention programs are often rejected (Madan, 1987; Mai, 1989). In rejecting the preventive aspects of disability

187

programs, community members may be defending the adequacy of indigenous culturally-bound methods for prevention (Stone, 1992). Alternatively, and especially so for people who lack professional rehabilitation services, prevention seems far less important than cure. People seek products that are tangible and immediate, and as a result, high-technology rehabilitation interventions are often viewed as the most attractive and promising option (Brownlea, 1987). CBR's emphasis on prevention has been rejected for another reason however, and that is this: What is the point of identifying people with disabilities if there are no services that can be provided? This is a difficult question. Disability screening may not really be that beneficial at all.

There is growing agreement in the South that dramatic proof of project benefits may be the only way to secure community interest in disability. In Indonesia, for example, surgical correction of club foot deformities has become essential for the Solo CBR Center (Solo CBR Workshop, 1995; Sutopo, 1993). Parwati, a mother of a disabled schoolboy said,

> We wanted nothing to do with it! We are too busy. But then they offered the operation. If we could collect enough money. I had to convince my family and neighbours to help, but every house agreed to set aside money for some rice every month in a separate bowl. In the spring we sold it. It only paid for his special shoes, but it meant they would take our case. He can walk now. I praise God every day! He will always limp, but he is not a cripple any more!

Many CBR projects, and virtually all IL projects, do not have the financial resources and medical affiliations that the Solo CBR Center has. As a result, sustaining long term commitment to disability via a community development approach in the South has been

188

a difficult endeavour (Krefting, Krefting, & Tjandrakusuma, 1993).

IL has encountered similar difficulties in its efforts to raise the profile of disability. One of the primary difficulties has been to translate IL's fundamental principles into terms that are culturally meaningful. Dr. Maya Thomas, a psychologist and disability spokesperson in India states,

> What they don't understand is that people with disabilities don't want it. They don't need it -- IL type advocacy. The reason they don't want it is that they would rather be part of their own family. They want close interconnections with their families. So why encourage independent living? These people are looked after. They are fed, cared for. I mean sure, they could be less protected than they are, be more independent and treated more as individuals. But within the cultural structure that is how everyone is treated. Don't set them up as something special! You must pay attention. Extended families are still alive and well in most of Asia! Although its changing. So, in some areas it is and in some areas it isn't, or in varying degrees, or its breaking up. But it's still there. It is a social force that is very positive. So why come in with independent living?

Dr. Thomas raises several important issues. She identifies the tension, discussed earlier in this chapter, between institutional protection for people with disabilities and the Western attitude of individualism and autonomy. Particularly in the South where formal rehabilitation structures and services have been very limited, basic protection and care remain an important part of the support system for people with disabilities. Thomas also reminds us that people with disabilities in the South have rejected elite leadership under both IL and CBR configurations. She reminds us that IL and CBR's ideas about what is good for people with disabilities rarely penetrates the village level. Heavily influenced by its development in the West, IL and CBR often conflict with

189

cultures where caring and communal protection are well established norms. An emphasis on attitude change, education and disability prevention has not captured the widespread excitement associated with corrective orthopaedic surgeries either. There are rarely quick and easy answers to disability problems. And IL and CBR have been deeply challenged by the myriad of problems confronted in their efforts to address them.

**Inclusiveness and Exclusiveness in the Definition of Disability**

If there is sufficient community interest in disability, one of the first steps in the implementation of a program is understanding what is meant by disability. The international experience has shown that determining who is and who is not disabled is far from straightforward. Ingstad and Whyte (1995) have described the tremendous variation between countries and communities as to what constitutes disability. However, the official definition of disability and the disability statistics generated from such definitions may not be the same as those held by the so-called community.

This research supports the contention that studying the definition of disability is fraught with difficulty. We are forced either to commit ourselves to a universal definition or to atomistic ethnographic studies suggesting smaller area variations. There are major problems associated with each. First, and as this research has shown, both IL and CBR tend to represent disability as a shared universal definition which plainly is inadequate to describe the diversity and complexity of global disability. This is demonstrated by such a simple example as the following: Mental impairments such

190

as mild learning disabilities are simply not recognized as problems by local people including health officers in many parts of rural Indonesia (Lysack, 1992). The same is true for physical impairments like limb deformities. The label disabled is only attached when people are unable to perform their normal social tasks (Lysack, 1995). Ingstad and Whyte (1995) are correct to argue that what is considered normal is highly dependent upon the society in which the norms are generated. For IL and CBR then, far more attention must be paid to the local understandings of the causes of disability, its personal and cultural meaning, the nature of appropriate therapies, and local attitudes toward disability. This knowledge is far from complete.

This research also supports the speculation that the meaning of disability can vary tremendously, even between closely proximate villages. Deschesne (1995, March) notes that small differences in historical exposures to colonial health systems, minor differences in economic structures, and slight variations in religious interpretation can make the difference between successful community based disability initiatives and struggling ones. Deschesne states that while people with disabilities in Indonesia are definitely seen as different, their degree of otherness is related to factors beyond their physical or mental limitations. The incident related earlier about the business people not identified as disabled because they were a financial success is an example of this. Their economic success meant the label disabled was not attached. While we may not be able to determine whether this incident represents an example of the variability in the definition of disability or whether it represents variability in the adaptation to disability, the end result is the same: The community did not share CBR's view of

191

what disability was.

In addition to variability in local understandings, the disability definition is subject to change for another reason. The reason is that progress in the disability realm serves the interests of various levels of government. In rural Indonesia, local health officials are rewarded for their achievement of various general health and social development goals (Dove, 1988). Health officials therefore encourage competition between villages with respect to the number of children vaccinated, the condition of village homes, the number of CBR cadres trained, the number of disabled infants screened at the *posyandu*, etc. This information is regularly updated and posted on the walls of the *puskesmas*. But do these strategies, even if implemented successfully, actually help people with disabilities in any meaningful way? A further question is the extent to which disability statistics are manipulated by government authorities in attempts to secure personal benefit. Official disability figures may be so completely unreliable that they are of little practical value (Kirshner, 1990).

Finally, it must be noted that definitions of disability are not only locally specified, but also locally contested. The international disability scene is replete with such examples. One of the most important lessons to take from this experience, as Vanneste (1994) puts it, that "people will often only attribute `problems' to the disabled member once services are being offered by a project" (p. 7). What counts as disability then, depends on what benefits accrue to those who claim the label. Ideological proponents of IL and CBR seem surprised to see participation in disability projects motivated by personal needs. They appear to expect wholesale altruistic commitment.

192

The issue of paying community based disability workers provides a useful illustration.

One of the most basic assumptions of IL and CBR ideology is that mutually

supportive villages exist, places where community members are willing to work without

personal gain toward improvements for all. Laura Krefting says this a profound

miscalculation. She claims IL and CBR are wrong to assume people want to serve as

volunteers, no matter how empathetic they might seem to be. She says,

> Paying volunteers? Absolutely! Unless people have a spiritual motivation, they
> won't do it. It is very naive to think people will keep doing it for nothing.
> They won't really be doing it. I just think you have to acknowledge human
> motivation. If they think that it's part of their commitment as being Bhuddist or
> Hindu then maybe they will. Muslims give money during Ramadan, and boy,
> they give lots of money! But they do not give time. It is very difficult to get
> people to do disability work. So you have to figure our either how to give them
> a lot more status than they have now -- and usually giving them that status
> means they aren't actually doing a lot, or give them social opportunities that
> they might not otherwise have, or a motorcycle they might not otherwise have.
> I think it is impossible to expect them to do it out of good will. Maybe in
> families with disabled, family members will be volunteers. But still, you know,
> they're the ones with limited time.

As Krefting suggests, efforts to improve the lives of people with disabilities ought to be

recognized. IL and CBR use the language of community in such a way that assumes

community members will participate as unpaid labour. But such levels of involvement

must not be expected without compensation. If monetary payment is not forthcoming,

perhaps new skill acquisition will suffice (Lysack & Krefting, 1993 & 1994). Krefting

continues,

> The crucial thing is skills, it's not just ideas. You have to give people tools to
> do community disability work. And not very many people have done that. It is

not just giving them training, showing them how to do it. It's being there. It's being in a meeting and figuring how to get money for income generating projects and figuring out how to make sure it doesn't get stolen by the village head! There are lots of technical skills that people haven't paid any attention to. You think they will develop it all by themselves but it doesn't. You can't just plant the seeds, go along and give the ideas, and then think it will grow. It just absolutely can't. The district heads here during the evaluation said: "You didn't tell us what to do next." Hmmm. That's very telling. There needs to be a lot more attention to the exact skills people need at different levels. You just can't expect to give them the idea about empowerment and all that and then expect they will get all excited about it and go do it. I think that is where a lot of programs have failed. They have not spent enough time. The nice ideas about the community and empowerment, they just don't cut it.

In summary, the successful implementation of IL and CBR depends on many factors. First, there must be a common understanding of disability and community. Second, the competing interests of government officials, disabled people, and community based disability managers and workers must be recognized. Particularly in contexts where resources for disability are limited but in high demand, there will be stiff competition between stakeholders -- not only to ensure that their specific interests are represented, but to guarantee their fair share of societal benefits. The issue of who counts as disabled is contentious. And general community development goals and the specific needs of disabled people at times collide. Complete commitment to IL and CBR is hence an illusion -- an illusion generated by very positive assumptions about the nature of community.

## Recruitment of Disability Workers

Once criteria for defining disability are in place, managers of community based

194

disability projects focus on the recruitment of community workers to perform various tasks related to disability awareness and rehabilitation. Ideally, disability workers come from the towns and villages in which they work. It is also preferable if they reflect the local demographic and cultural profile (Walt, Perera & Heggenhoughen, 1989). Often this is not the case however, and problems arise. This research suggests that the problems are related, at least partially, to CBR's geographical understanding of community and IL's understanding of community as identity and belonging.

In selecting its community workers, CBR is most concerned about representing the views of what it sees are the most prominent groups in the geographical area. The involvement of religious leaders, teachers, health officials and families of people with disabilities for example, is solicited. The best participants are thought to be those who are most efficient in communicating the CBR message, visiting disabled people in their homes, and carrying out CBR activities such as disability screening. For IL however, the approach is somewhat different. IL workers do not tend to be found in population clusters in physical localities, as in CBR. Community for IL is something more diffuse. For IL, ideal representatives are concerned about the rights claims and benefits of disabled people. Prominent advocates and successful people with disabilities who can serve as role models, sometimes including family members, are typically selected as disability workers. There is a difference between workers selected on the basis of commitment to an ideal and those selected for their effectiveness in getting the job done, however. The YPAC CBR Center in Solo exemplifies a case where these objectives came into conflict within a single organization.

The Solo CBR Center has deliberately chosen to engage the assistance of the Indonesian Women's Family Welfare (*Pembinaan Kesejahteraan Keluarga* or PKK) to serve as CBR cadres (PPRBM, 1991; Roestam, 1988). The PKK is organized from the national to village level, and has established duties in the *posyandus*. Using PKK members as cadres offers several advantages. First, PKK cadres are already familiar with the villages in their areas. Because they possess some prior health knowledge as a result of related activities as nutrition cadres, their training with respect to disability is thought to be less extensive. Importantly however, they may lack specific expertise in the area of real disability prevention and local level interventions. Reliance on elite PKK cadres also risks alienating other villagers who do not share the same values and may not agree with PKK priorities. For one thing, PKK cadres are of considerably higher socioeconomic status than ordinary villagers. Many are the wives of government officials, so they can also get caught between conflicting personal, organizational and community agendas. As members of a quasi-political organization, female PKK cadres are sometimes called upon by virtue of their husband's affiliation with government, to support a health policy not in the best interests of CBR. Without their substantial contribution through unpaid labour, however, implementation of CBR would be almost impossible (Papanek, 1982; Rienks & Iskandar, 1988). This poses a real dilemma for CBR and it highlights once again the trade-offs related to elite representation.

The recruitment of disability workers is also linked to the issue of payment. There is mounting pressure in the South to professionalize the unpaid sector who

provide the real labour for IL and CBR projects (Balasundaram, 1994). In India for example, the government is calling for standardization of CBR curricula and the development of a career laddering structure for CBR workers. There is another fear, however, and that is that the government's interest in CBR is driven by a desire to save money (i.e., by replacing more costly medical institutions and professional personnel with unpaid or lower paid workers). While there is significant intercountry variation on this issue, the case of India may foreshadow a broader trend. The Indian proposal includes control over the definition of disability, apparently to make the standardization of eligibility criteria for services more consistent. If this legislation passes, despite the rhetoric of community ownership, CBR will be largely controlled by those external to the physical localities and the people whose needs community based disability services are for. In addition, by creating a new cadre of consumer expert, CBR may inadvertently hasten the shift of responsibility away from professionals and rehabilitation facilities and onto families. The shift to community in the Indian context must still be differentiated from the situation in the United States and Canada where there has been a significant transfer of formal health services from national health ministries and publicly supported community programs to an unwilling volunteer sector. Community thus becomes a strategic assertion to mark the devolution of real responsibility and work regarding disability. This issue will be explored in more detail in the following section. Suffice it to say, that while empowering the community is a phrase frequently employed by disability projects around the globe, it is less than clear who the community *is*, and who decides what *they* really need.

197

## Community Mobilization

Since the essence of CBR and IL is community participation, it is important to understand the extent to which communities have actually become involved in CBR and IL initiatives. The reality is that a disability rights consciousness is only just emerging in a few countries in the South. People with disabilities in many other countries are struggling to obtain basic health services, let alone rights, and social and resource entitlements. While CBR has been somewhat more successful in attracting the attention of governments in the South because it potentially offers a less expensive means to address disability issues, even CBR must struggle to ensure disability remains a priority of health ministries and professionals. Generating and sustaining governmental interest in disability is only the first step, however. Proponents of IL and CBR must also sell the concept to the community. They must convince ordinary people first, that the aim of assisting people with disabilities is a worthy goal, and second, that a community development approach is the best means to achieve that goal. Their argument is highly reliant upon the notion of democratic participation, an ideal assumed to pre-exist in the community.

One major threat to community mobilization is the fact that some communities view rehabilitation as a government, not community, responsibility and do not become involved at all (Lysack & Kaufert, 1994a). In contexts where there is no social safety net though (i.e., the majority of Southern countries), IL and CBR can hardly be viewed as returning decision making control to the people. Quite the opposite. Critics of IL and CBR argue that community is simply a nicer word than family, but that in reality, it

198

is family members who carry the burden of disability and IL and CBR activities. Arne

Husveg (1995), President of the European Blind Union, states

> In a developing country, most families struggle to stay alive. One non-
> productive member means an extra load on a family economy which is already
> stretched to the limit. Is it acceptable philosophy to assume that such families,
> in addition to their struggle to keep their heads above water, also take
> responsibility for a service which is the obvious responsibility of society?
> (p. 20)

If community really does mean family, then the rhetoric of communities taking

ownership of disability is wrong. This disguises the unpaid work of families in caring

for their disabled relatives. There may be nothing empowering about this. If, on the

other hand, community does not mean families but rather paid disability workers who

provide outreach services, then once again, official CBR policy statements which read:

"The community is the power base behind CBR" (Peat, 1990, p. 14) come into

question. Both ways, the language of community misrepresents what actually occurs.

The problems caused by the various interpretations of community are

encapsulated in the comments of Dr. Manik Shahani (Shahani, 1990).

> CBR will shift the management of disability and dysfunction from highly
> sophisticated institutions to more simple, easily understood programmes which
> can be delivered in the environment of home or neighbourhood.... Home based
> treatment programmes have a chance of success only if at least one member of
> the patient's family is an active participant in the treatment programme....
> Professionals who have been trained in sophisticated departments may have
> difficulty adjusting to the limitations of space and equipment as well as the loss
> of confidence which comes with working in one's own territory. They may
> wonder if they are giving their best to their patients, considering the knowledge
> and skills available in institutions. (p. 5)

In addition to increased family responsibility however, Shahani appears to assume that

CBR will be delivered by professionals in the homes of disabled people. He is not

alone in this understanding. A similar expectation is held by a second disability expert

in India, Professor Ganeesh Purohit. Purohit (1990) asks,

> Is CBR an outreach service where professionals come to advise local
> authorities? Will professional services also be decentralized? How can this
> dream be realized? ....It will take time to select people from within the
> community to take responsibility, as few people in the rural areas have any
> education. A proper infrastructure must be built. (p. 39)

It appears that for some, CBR is an extension of professional rehabilitation to under

served, rural areas. So is CBR professional outreach or is it grassroots community

development?

There are other challenges to community mobilization and without close

attention to the meaning of community, improving the quality of life for people with

disabilities in the community via a community based approach will remain a challenge.

A second major difficulty is that poor and disadvantaged people, including people with

disabilities, may discount the participatory approach of IL and CBR, instead preferring

professional and governmental handling of community health problems (Stone, 1992).

When this is the case, Il and CBR projects will be very difficult to initiate. Kalangie

(1995, January) reminds us that peasants are essentially powerless. All basic decisions

are made for them by people of higher economic, political and religious standing. For

generations in Indonesia, he states, the initiative "has been drummed out of the people."

Kalangie says, "The peasant can never the know the reasons for decisions. He can

200

plead ... and hope for a miracles, but in neither case can he expect by his own action to have any effective control" (p. 8). Against such a backdrop, implementation of new disability projects using community participation is a major challenge, no matter how accomplished its proponents. Planners and managers of community based projects must remember that people do not automatically know how to participate, and many have never engaged in cooperative community initiatives.

Not only can the participatory approach advocated by IL and CBR be completely foreign, it can be threatening as well. San Yuenwah is with the Social Development Division of the UN in Bangkok and is in a position to appreciate the Asia-Pacific progress with respect to national implementation of rehabilitation programs. In her estimation, a community development approach brings with it substantial benefit. However, she believes projects must move more slowly and appreciate more deeply what the community actually wants. Yuenwah says

> Some people are not involved in disability projects or do not choose to be involved. We should respect that. You know, there are often kindly advocates running everywhere promoting projects and doing good. But the people may not want to be done good to! They must be given that choice. Remember the "must" in community participation is our must from our educated, Western values. If they want it, let them have it. Otherwise, let them alone for awhile.

Community mobilization is curtailed when there is disagreement over whether disability should be a local or government responsible, and when participatory strategies are unfamiliar. In addition, top-down administrative hierarchies are sometimes so entrenched in countries that anything participatory is viewed with suspicion. CBR and

IL implementation, highly reliant upon mutual learning techniques, are also viewed

with suspicion in cultures which do not value group decision making and consensus

highly. In Indonesia for example, long traditions of obedience to authority mitigate

against participation (Koentjaraningrat, 1985). Indonesians have been historically

dominated by internal political structures such as the generations of kingdom rule, and

by authoritative structures imposed with the country's occupation by the Dutch and

Japanese (Henley, 1992).

Interestingly, however, there is also some evidence to suggest that disability

projects implemented via a top-down administrative approach would have failed

operationally with less of an authoritative structure. This state of affairs, surprising to

many Western CBR and IL leaders, is most common in countries where local people

have not been used to taking decision-making responsibility. The top-down approach

may also be necessary in contexts where disability would otherwise receive no attention

whatsoever. An Indian rehabilitation physician attending the RI Conference in Jakarta

stated,

> I just want to comment on one thing ... and that is about community perceptions
> of their own needs and the priorization of disability being a need at all. We
> have found that when you are struggling to survive, sometimes the priorization
> of disability comes only with a top-down approach. We have found sometimes,
> in order to get the process started, sometimes that is the only way to begin. By
> going into an area and promoting disability. Only afterwards, then we start to
> talk, and then we let the community take over.

It is important to recognize the diversity of contexts in which IL and CBR operate.

## The Costs of a Community Approach

IL and CBR's emphasis on community participation implies certain community costs. These costs may be financial, as in fundraising. More often, however, the costs take the form of time. While there is some evidence to suggest that people are motivated to participate in disability projects for the associated gains in social prestige, personal development and access to urban centres they might not otherwise visit (Lysack & Krefting, 1993), these rewards must be personally meaningful. Otherwise, poor villagers will not become involved at all, or their involvement will be token at best.

In previous research conducted with Indonesian CBR cadres, Lysack (1992) interviewed women who volunteered for CBR. Any assumptions about altruism should be dispelled however. Not all community members are waiting to aid their disabled neighbours. Lysack (1992) writes,

> Individuals do not usually come forward and request involvement with CBR, as may be the perception by the use of the word "volunteer." CBR cadres are chosen. Once local government authorities have been convinced of the utility of CBR, and have given formal approval for its implementation, the Head Man of the village begins selection of cadres. He consults with the Chairlady of the PKK in the village and requests that she provide him with a list of candidates. The list is generated at a village PKK meeting via the Chairlady's suggestions and is finalized via group consensus. This list is returned to the Head Man who may make revisions of his own. A formal letter of recommendation finally determines who the CBR cadres will be. It is important to note that some cadres responded to the question "Why did you volunteer to be a cadre?" with the words "I didn't choose to, I was told to do it by...." It is clear that a number of people did not want to be cadres but that they had no choice. When cadres are selected, it is virtually impossible to refuse the position. (p. 89-90)

In Indonesia, community based disability volunteers should really be described as recruited or strongly encouraged to become cadres. They have no real freedom of choice (Haliman & Williams, 1983; Williams & Satoto, 1981). In other countries as well, this balance of political, cultural, social and religious factors can have a very significant impact on community participation. The Bhuddist religious tradition, for example, strongly supports the concept of merit gained through good deeds (Kaseje, Spencer & Sempebwa, 1987; Miller & Khan, 1986). Lysack and Krefting (1994) also report that CBR cadres do sometimes feel a significant sense of moral obligation to their families, near-by neighbours and even their country -- an obligation that can be traced to religious factors and political indoctrination. One cadre said: "First, we must be the friend of our husband. Second, we are housekeepers. Third, we are educators for our families. Fourth, women are income-earners, and fifth, we are citizens. And additionally, it is the *Darma Wanita* (Women's Group) that helps to get voluntary programs going" (p. 5). In fact, Indonesia's political context is a major influence on all projects reliant upon community participation. Since Indonesia's independence from external political authority in 1945, the Indonesian government has continued to maintain a rigid hierarchical political and administrative system. But, Haliman and Williams (1983) suggest that within such a sociopolitical environment "initiatives from ordinary people outside the structure can be quickly stifled" (p. 1452), if the government deems it necessary. Such structures may create official community participation, but perhaps not real participation. For this reason, local participation around disability can be exceedingly difficult to generate and sustain.

Returning more directly to the issue of the costs associated with community participation, it is clear that when initiatives focus on the poor, the disabled, or other minority populations, utmost care must be taken so that the burden of organizing change is not solely placed on these already disadvantaged groups. Kenji Kuno is a Japanese physiotherapist who volunteered his professional services to the CBR Center in Solo during 1995 and 1996. He played a significant role in training rural Javanese women to identify disabled children and provide simple rehabilitation interventions. Presently volunteering in Sabah, Malaysia, Kuno says

> I want to share a major failure of implementing CBR. Teaching home exercises to parents, especially the mothers of disabled children, used to be done as one of the general CBR activities in the villages. However, these home exercises are rarely continued because most of the mothers' time is occupied by daily work and child care. We teach these exercises, and then we leave. And they don't do it. So does this help them? I think about this.

Similar concerns have been raised by disability activists in other parts of the world. Marjorie Concha is the Head of the Department of Occupational Therapy at the University of the Witwatersand Medical School in Parktown South Africa. She is also in charge of the Community Rehabilitation Worker Training Programme. Describing the daily life conditions of disability workers, Concha says,

> Especially in rural environments, life is very hard. People are often very tired. They are *always* working. They are not even always welcome where they arrive. They can't realize what people want them to do at first. Sometimes the villagers are expecting donations! The workers usually earn poor salaries or are even expected to work on a voluntary basis.

Lysack and Krefting (1994) add that "because of embarrassment or shame, the family may hide the disabled child or cadres may be afraid to work with them" (p. 5). One experienced cadre, Mrs. Mir'atun said, "My worst experience as a CBR cadre was when I wanted to help a family but they didn't like it because they thought we would show their disabled family members in public." Obviously, these conditions have a negative impact on disability projects. Marjorie Concha from South Africa continues: "For these reasons, sometimes, rehabilitation workers seem to have only a very limited interest in the results of their work. And if they are really interested, they don't take or find time enough to learn about the progress the persons have made and report too easily their findings and evaluations." Community participation also has a particular cost for women in the South who are the traditional caregivers of the infirm. This has real and profound implications for the health of the community overall (Lysack & Krefting, 1993). Douglas Krefting, who managed the YPAC CBR project in the early 1990s and is now responsible for a similar project in Bangladesh, confirms that disability projects ask an enormous amount of women. Krefting says,

> I don't like to use the term burden, but I guess it is as good a word as any.
> Women and women with disabilities are a major force in CBR -- because
> women are the caregivers. That's a universal all over the world. When I was
> sick, my father didn't look after me. When you were sick, your father didn't
> look after you. I mean, he paid attention to you and all the rest of it, but who
> looked after you? That was your mother. If you are a child with a disability, so
> long as we have a male dominated society, it will continue to be the woman.
> You will find women do the real compassionate work in the world.

Unless the costs involved in participatory activities are taken into account, only elite

206

individuals will become involved in community based disability projects, thereby excluding and possibly worsening the position of lower income and less powerful community members.

The final major problem pertaining to community mobilization is the issue of service quality. Simply put, nobody wants second-class services. If CBR and IL are perceived to be rehabilitation on the cheap, then they will be rejected by those with the means to obtain better (Lysack & Kaufert, 1996). The essential difference between IL and CBR should be re-emphasized at this point. IL is not a service delivery model, nor is it intended to be. IL developed in response to the over penetration of professional services into disabled people's lives -- a situation essentially unknown in most countries in the South. CBR, on the other hand, was developed to address the shortfall in professional resources. Community based programs in the South, as sponsored by IL and CBR, are both sometimes viewed as a replacement for professional, institutional rehabilitation. Dr. Tran Trong Hai is the Head of the Rehabilitation Department at the Institute for the Protection of Children's Health in Hanoi. He is also the Institute's CBR Coordinator. During the Pre-Conference Workshop on CBR held in Solo, Dr. Hai described in some detail the ingenuity of rural Vietnamese civilians left amputees by the devastating legacy of landmines and how they have creatively devised simple rehabilitation equipment to assist in their activities of daily living. However, he also described amputees injured in other ways who live in the wealthy areas of Hanoi. This latter group are presently demanding and obtaining top quality prosthetics. Some, for example, are purchasing state of the art ankle-foot-orthoses for more than US $500.

207

These individuals are not prepared to sacrifice technical quality, physical comfort or

cosmetic appearance. Dr. Hai believes that while the ongoing debate within CBR about

the merits of a bottom-up versus top-down approach may never end, he is convinced

that community mobilization around disability will never be achieved if people do not

view CBR as providing a quality product. Similar sentiments have been echoed by IL

spokespersons. IL must be seen as valuable and not a poor replacement for

unaffordable professional rehabilitation. A Swedish rehabilitation engineer and

disability advocate stated,

> At the Indonesian Conference, if you asked any one of those participants, all
> preferred traditional, hospital-based rehabilitation to community-based services.
> Community disability projects must not be the cheap, low-tech solution for
> developing countries because they don't deserve better. There must be caution
> around believing developing countries somehow deserve less.

IL and CBR proponents must contend with the image of community based disability

interventions in the South as a technological fix. The media inadvertently promotes this

tendency because media images diffuse broadly long before the rehabilitation

infrastructure is in place. Villagers rightfully fear that in some instances CBR means

replacement of what limited professional services they have with more limited services

delivered by unpaid volunteers. The accelerating pace of economic modernization also

means that communities in the South are becoming increasingly aware of what they do

not have. There is also the ongoing concern that in moving toward an elimination of

institutional rehabilitation, a major reduction in total resources for disability will be the

result. Husveg (1995) of the World Blind Union agrees: "People advocating

208

community-based rehabilitation always point out that it is so much cheaper than traditional rehabilitation. This is undoubtedly true. I am tempted to reply that no rehabilitation at all is even cheaper" (p. 20). This is indeed a complicated issue. In the first place, there are elite disabled consumers with cosmopolitan access to international biomedical technology. The second group of disabled people is much larger than the first, and while they cannot afford sophisticated disability equipment, they do not necessarily embrace the appropriate technology ideology pushed by some Western IL and CBR experts. Instead, they seek whatever is available, because it is better than nothing. An exasperated Paul LeJeune from CCD in Winnipeg explains:

> You've got people in the West telling developing countries to go with appropriate technology. Then you can get parts, fix it there, and all that crap! Well, maybe that's true, but how do you tell a guy crawling, dragging his stumps in the dirt on the road, that you won't ship him over an old wheelchair that is just going to a landfill site because its not appropriate! I can't look him in the eye and tell him that, can you?

One of the major outcomes of the Solo CBR Workshop was the conclusion that the greatest success in community based disability has been achieved when disability is incorporated into broader community development strategies. A community development approach integrates disability into every facet of community activity, from childhood education to nutrition, from agriculture to sanitation, from family planning to income-generation. In short, project success must be predicated on the assumption that disability matters permeate all aspects of community life. Ron Chandran-Dudley of DPI Singapore says,

You know, what a disabled person really wants is to be under the sun, just like his neighbours are. Under the sun. But I say, they must also be prepared to be under the rain, as his neighbours are, under the rain. In other words, they are equals. They want equal opportunities. Then, we must understand that we can't always be "good for the disabled people" and not for the others, and vice versa. It cannot always be good for the non-disabled and bad for the disabled. It has to be in tandem. I don't know whether that is considered to be an idealist situation. But I think with all our information, if we can bring about the kind of philosophy that is acceptable globally, that we need to develop all systems, all human methodologies, all services for people with disability at the same time as you are doing it for all others. That would be excellent.

Attending only to the special needs of disabled people will not be productive.

Disability projects must extend more broadly into the so-called community. In other

words, community based disability projects must be more inclusive. Prominent

international CBR leaders appear to agree with Chandran-Dudley and other key

disability movement leaders on this critical point. Dr. Handojo Tjandrakusuma,

Director of the Solo CBR Center, for example, captures the sentiment in this way:

> There are many issues in the community that are not disability issues. When we stress too much on disability, it is not the issue of the community over there. This is a dilemma. That's why we must not push the community too hard to provide services for disabled people only. It must be balanced. Disabled people do need something more. On that we agree, of course. But you cannot go too far and ignore the rest of the community. We are one and many at the same time.

Dr. Handojo is suggesting that pursuing only specific benefits for people with

disabilities is not the answer. Greater attention to the rest of the community is

imperative. Thus, the idea of community for IL and CBR must be expanded.

Community must be more inclusive.

210

## Summary

Both IL and CBR ideology claim community based projects represent the best approach to improving the lives of people with disability worldwide. Community participation assumes a central role in the implementation of these projects because lay people are assumed to hold important knowledge that experts and specialists do not. Community disability projects then, guided by IL and CBR philosophy, carry an ingrained and mostly unconscious optimism, that disability problems are best dealt with by a reorientation toward community. This critical analysis of community in the international discourse of IL and CBR has shown this conclusion to be premature. The analysis in this chapter suggests that the matters of community needs identification, community participation and community representation are complex. There are serious questions about the cross-cultural portability of disability ideology, for example. Culturally, key principles may not be recognized as relevant or particularly meaningful. Second, significant assumptions are made by IL and CBR about the egalitarian nature of communities and the likelihood of democratic participation. As this research has shown, these assumptions can be quite wrong. Elite leadership issues and internal divisions within IL and CBR create real difficulty in this regard as do the substantial socioeconomic divisions that exists between North and South. Hence, the supposed community of caring and empowerment generated by IL and CBR ideology may exist more as fiction than fact. Without a more critical perspective, all strategies to provide interventions for people with disabilities in the settings in which they live will remain less than they could be.

211

# THE GOOD SOCIETY

## Introduction

In this thesis research I have argued that the community of IL and CBR are distinctly different entities. While similarly employing the language of community, IL asserts a community of identity while CBR asserts a community of geography. Because the idea of community influences the actual programs designed and delivered by each ideology, the way in which community is understood has real implications for both the orientation and ultimate success of these programs.

The research has also argued that there is a dissonance between the expected features of communities and those found. This can be explained by a tendency to abstract positive features thought belonging to communities of a simpler, more traditional, and more primitive past, and then applying them to the present. Not only have some features of historical community been ignored in this process, unique features of contemporary community have been left unexplored. As this research has argued, this view of community has contributed to problems associated with the implementation of IL and CBR as community based approaches to disability has been the primary objectives of the thesis research.

In this final chapter of the thesis, findings generated within international IL and CBR will be extended more broadly. The chapter is divided into four main sections and is organized as follows: In the first section, we return to the idea of modern malaise first mentioned in the Introduction. Here, the suggestion will be that the

pervasiveness of community language in our contemporary time (as in all time) functions to mitigate this malaise. It accomplishes this by sustaining a powerful nostalgia around the conception of community. In the second section, the nature of community in our postmodern time is examined. Here, the focus is on groups calling themselves communities that possess features quite unlike those typically connoted by the term community. The criteria for and process of social policy formulation directed to groups called communities is examined next. The importance of critical postmodern research is also defended in this third section. The final section of the chapter provides a brief synopsis of the main research findings and its primary theoretical contribution to social research.

## Community and Existential Malaise

Unlike other central concepts such as liberty and justice, the literature on community "frequently appeals to images of community without giving the notion the analytical attention it deserves" (Mason, 1993, p. 215). It is further evident that the concept of community, and its place within social theory more generally, has undergone a number of important shifts. Alexander (1995) provides an excellent treatment of this topic. Community was a central theme during the social transformations in the late 1880s, a part of civil unrest and dissatisfaction in the 1960s, and again at the close of the millennium has reasserted itself as evidenced by the veritable spate of political scientists and social philosophers who have begun to investigate its current social fashionability and theoretical utility (Etzioni, 1996; Benhabib, 1992; Fowler, 1991;

213

Habermas, 1984 & 1987; Selznick, 1992; Saul 1995; Taylor, 1991). The deep penetration of the idea of community in the international discourse of IL and CBR coupled with the diverse and interdisciplinary nature of the interest in this concept suggests community represents something which is quite fundamental to human existence and experience. We may ask then, do these images represent a deeply perceived human need which cause groups to strive to embody one or several of these community images?

## The Malaise of Modernity and the Rise of Global Culture

The world is in dramatic flux and so are the relationships between individuals and their social groups. The nature of these groups, sometimes called communities, are also changing. Changes wrought by global capitalism have much to do with this period of societal transformation, and while communication and information technologies have not caused the social upheaval, they have certainly accelerated the pace (Fisher & Kling, 1991; Shefner, 1995). Huge changes in macro relations among governments and the international economy have left individuals at the micro level not only economically vulnerable but socially exhausted as well (Ehrenreich, 1989). Feeding this social fatigue is the increasing disappearance of many of our traditional guideposts, perhaps including that of community. Taylor (1991) notes, community affiliations are no longer dictated by external authorities such as natural law or divine rule. This loosening of the ties that bind have transformed geographical communities and communities of identity into communities of choice. Touraine (in Fisher & Kling,

214

1991, p. 78) calls this phenomenon a breakdown of the "metasocial warrants of the social order." We are condemned, according to Taylor and Touraine both, to an unending cycle of chosen identities that are discarded when their usefulness is outlived.

This change in the relationship between the individual and others in society is possible because the late 20th century is the most individualist society in human history. As stated in the Introduction to Chapter 1, unfettered personal freedom helps to explain our present civil atrophy.

> We are free to plot our own course, plan our own lives, choose a career, a partner (or succession of partners), a religion (or no religion), a politics (or an antipolitics), a life-style (any style) -- free to "do our own thing." (Walzer, 1994, p. 187)

Chosen identities are not fixed identities, however. Walzer (1994) continues,

> These identities are mostly unearned, without depth. Footloose individuals are not reliable members. There are no borders around our cultural groups and, of course, no border police. Men and women are free to participate or not as they please, to come and go, withdraw entirely, or simply fade away into the peripheral distances. This freedom, again, is one of the advantages of an individualistic society; at the same time, however, it doesn't make for strong or cohesive associations. (p. 188)

This contemporary condition, perfused as it is with images of multiple identities, cultural normlessness and crumbling social institutions has been examined in detail by Ehrenreich (1989) in her book *Fear of Falling*. Ehrenreich suggests that relentless economic change and the negative social spin-offs it generates has given rise to a reconstructed, more disciplined self. Survival in contemporary environment requires a

215

mercenary frame of mind. Personal needs are the priority, and only where time and

energy are surplus (and most often they are not) will concern for others exist. Pilisuk,

McAllister and Rothman (1996) agree. These authors contend that individuals are

scrutinizing their community affiliations and participating only where they calculate

maximum benefit. But if contemporary community is characterized by transitory

affiliations between individuals and selfishness, how do we explain the intense interest

in community in recent years?


## The Function of the Idea of Community

Bauman (1996) claims there are many torments in contemporary life, but they

all boil down to "the noxious and sickening feeling of perpetual uncertainty in

everything regarding the future" (p. 85). If this is so, and I believe it is, then what

function does the idea of community serve in relation to it? It is my contention that the

symbols embedded in the notion of community have certain functions in society. One

of these functions is to alleviate the uncertainty of modern life that Bauman speaks of.

Community is (re)quested today because it (re)presents a way out of the indeterminate

present. Community is thus a counterpoint to the anomie of modernization.

Cameron and Gatewood (1994) have explored the contemporary currency of

history, heritage and nostalgia in some detail. I believe their analysis is directly

relevant to our discussion here since the quest for community often contains nostalgic

elements. These authors state that nostalgia serves several social-psychological

functions, but two emerge as dominant: First, nostalgia may be a slowing mechanism.

216

The search for community may therefore represent "a psychological adaptation to circumstances of rapid culture change during which individuals fear becoming obsolete" (Cameron & Gatewood, 1994, p. 30). When the pace of technological and economic development is too fast, individuals and organizations seize on the notion of community to slow the process down. Cameron and Gatewood (1994) say: "Whenever societies become fearful about the future and lose confidence in their way of life, people will seek emotional solace and security in the safe certainty of the past" (p. 30).

Second, nostalgia provides a calming balm of hope. Imagining a simpler "community" time allows people a greater sense of control over their lives, and in time, a deeper optimism. Cameron and Gatewood (1994) state: "Alienation is so much a part of contemporary life that people seek to gratify emotional needs for connectedness and community by going back in time (or elsewhere) to find a simpler, gentler life" (p. 30). The idea of community thus represents a way to mitigate contemporary existential malaise by recapturing elements of an ideal form of community (perhaps real, perhaps mythical) and applying them to the present.

## The Nature of Contemporary Communities

In this section we will examine more closely the essence of contemporary communities, be they communities of identity or geography. We have already seen in the previous section, and in earlier chapters, that different kinds of community exist. We have further observed the gap between the kinds of features expected in these communities and those actually present. The gap represents the essential difference

217

between what we have been calling traditional and contemporary features of the idea of community.

One of the main differences between the idea of traditional and contemporary community is the transitory allegiance of contemporary community members. Contemporary individuals belong to multiple communities which function in overlapping spatial and temporal ways. They move in and out of these communities for specific reasons and to accomplish specific goals (Pilisuk, McAllister & Rothman, 1996; Rosenau, 1994; Shefner, 1995). That people are capable of living in many different kinds of communities simultaneously is due, in part, to the wide variety of groups which are recognized as or assert community status.

Sometimes the word community is used so broadly that it is difficult to know where the boundaries of the community are or who is excluded such as in "the international community." At other times it is unclear whether those identified as belonging to a certain community could have a consciousness of such belonging as in "the mental health community." Mostly however, we observe that group leaders, and perhaps group adherents, self-consciously choose the label community with a view to imbuing their particular group with the positive attributes, and thus societal legitimacy, or what I am calling here traditional community. Significantly, in our society, community is largely self-definitional; that is, we are a community if we say we are. Many communities formed with specific purposes in mind have as those purposes increased claims on societal resources on the grounds that they are or have been oppressed or disadvantaged in some way. This is not a feature of traditional

218

community. Contemporary individuals choose to belong to a particular community for personal reasons, although the community is seen as an empowering vehicle. The individual has few bonds to other individuals in the community apart from their common goals, and little or no concern for the welfare of the community as a whole. The community as a whole in many cases is devoid of content and can be viewed simply as a collection of individuals who wish to achieve certain individual goals.

Thus, there is a growing sense of entitlement that characterizes the community discussion. Individuals comprising communities of choice are seeking satisfaction of individual needs. With the fragmentation of contemporary identities however, virtually everyone can find a community to belong to. Left totally to their own devices however, these communities of choice open the way for a reactionary retreat into the politics of culture, or what Ignatieff (1994) calls the "narcissism of minority difference." This narcissism has found expression in the discourse of personal rights.

Rights have taken on a new tone in the contemporary world in a similar way to community. Rights are no longer just basic rights as citizens, but also additional rights the individual feels entitled to by virtue of membership in a particular community. Old notions of cultural pluralism and multiculturalism have disappeared. They have been usurped, as Walzer (1994) writes, by a disjointed cacophony of competing interests.

> The voices are loud, the accents various, and the result is not harmony -- as in the old image of pluralism as a symphony, each group playing its own instrument (but who wrote the music?) -- but a jangling discord. It is very much like the dissidence of Protestant dissent in the early years of the Reformation: many sects, dividing and subdividing; many prophets and would-be prophets, all talking at once. (p. 186)

219

Just as community itself is largely self-definitional, so too are the claims of community. As Hughes (1994) puts it, if you feel oppressed you are. Few have set out the problem of rights more definitively than Henry (1994) who, in his provocative treatise *In Defense of Elitism* writes,

> We have foolishly embraced the unexamined notions that everyone is pretty much alike (and worse, should be), that self-fulfilment is more important than objective achievement, that the common man is always right, that he needs no interpreters or intermediaries to guide his thinking.... We have devoted our rhetoric and our resources to the concept of entitlement, the notion that citizens are not to ask for what they can do for their country, but rather to demand what it can do for them. The list of what people are said to be "entitled" to has exploded exponentially. (p. 12-13)

How do Henry's remarks, aimed at the unsatisfactory state of American social life, and the present discussion of the nature of contemporary community relate to the idea of community explicated in the previous chapters? The thesis has argued that both IL and CBR have been affected by what Henry (1994) calls the "myth of communal splendor." By privileging the local, the common, and the traditional, IL and CBR have sentimentalized the idea of community.

When people use the language of community, they often implicitly refer to what I have called here traditional community. Mutual concern, commitment, harmony, equitable sharing of community resources, and consensual decision making are some of its core elements. They do not imply the contemporary features of community. Two features of traditional community illustrate this point.

220

<u>Harmony or Coercion?</u>

Community relations are traditionally depicted as harmonious and equitable, but
as Wignaraja (1993) correctly argues, this model must be demystified because it ignores
power relationships within communities.

> The assumption of harmonious communities in a conflict-free social framework
> for change has no basis in reality, whether at local, national or global levels....
> In most Southern villages, deep-seated contradictions exist between different
> groups with conflicts of interests. There are sharp relationships of dominance
> and dependence. These relationships give power to the dominant (the
> landowner, the trader, the moneylender, the bureaucrat, etc.), bringing about a
> crisis of immediate survival for the poor. Serious divisions exist among the
> poor themselves, based on caste, religion, gender, age, etc. These divisions,
> the people's resultant reluctance to take economic, social and political initiatives
> collectively to improve their lives, and their inability to change their lives
> individually, further compound their difficulties. (p. 11)

Also, and in sharp contrast to the positive language, real communities of identity and
geography, at times can be coercive. Coercion is required to ensure threshold levels of
community commitment. Efforts to enhance community cohesion must also be
continuously reinforced, otherwise the group disintegrates with little chance to reach its
goals. As Pearson (1995) states,

> To earn the appellation "community," it seems to me, groups must be able to
> exert moral suasion and extract a measure of compliance from their members.
> That is, communities are necessarily -- indeed, by definition -- coercive as well
> as moral, threatening their members with the stick of sanctions if they stray,
> offering them the carrot of certainty and stability if they don't. (p. 47)

Importantly though, as soon as communities solicit commitment, they become
exclusionary, at least to some degree. Of interest is this question: At what point does

the necessary coerciveness or exclusiveness of a community become oppressive? (Young, 1990) In the case of disability, efforts to enforce community participation in IL and CBR activities may culminate in the replacement of a centralized tyranny (rehabilitation professionals and government health officials, for example) with a newer localized tyranny of power brokers (Ife, 1995). If this is so, then the problems of centralized authority and control are simply reproduced on a smaller scale.

Exclusion is the ultimate consequence of control and domination. The development of exclusionary forces within the context of health have been traced by Crawford (1994) who says the goal of health has become "an essential component of what it meant to be modern, progressive, rational, and distinctive" (p. 1348). Moreover, the language of health has come to distinguish between those "who were responsible from those who were not, those who were respectable from those who were disreputable, those who were safe from those who were dangerous, and ultimately, those who had the right to rule from those who needed supervision, guidance, reform, or incarceration" (p. 1348). Whereas the pursuit of health signifies moral personhood, a lack of responsibility for health implies betrayal, not only to people's bodies but to human progress as well. A very negative implication stems from this moral differentiation. Crawford concludes: "The misfortune of the Other will be of no concern because they are persons outside the collective circle of identity called community" (p. 1363). This is indeed a foreboding signal.

Significantly more work must be done to explore the circumstances under which communities can overcome their exclusionary tendencies. We have seen that traditional

222

community is a myth. We have also seen that the transfer of ideal traditional features

of the idea of community to actual contemporary communities has the effect of

alleviating to some extent existential anxiety, and also legitimating their claims. The

notion of community, therefore, is unlikely to be dispensed with any time soon. A

close examination of contemporary society shows that the word community may imply

empowerment and inclusion, exploitation and exclusion, and everything in between.

## Implications for Social Policy

In this third section of the chapter the theoretical backdrop which allows various

groups within society to call themselves communities unchallenged, and the difficulties

this poses for social policy development is examined. Because social policy is often

formulated with a view to assist communities in some way, we will look first at some

broad theoretical perspectives which informs the kinds of social policies which are

possible. A critical postmodern approach allows us to avoid several practical

difficulties in this regard. In the second half of this section, we examine the result of

allowing communities to self-define and to attach to themselves features of traditional

community, and using the example of IL and CBR discuss three significant problems

for social policy development.

### Cultural Relativism and Criteria for Meaningful Social Policy

The proliferation of communities in our society is the result of a cultural

relativism which regards as legitimate only the voice of the community. Thus,

223

observers are required to take the self-description of communities at face value. Cultural relativism, coupled with the connotation of community as good, and hence belonging to a community as good also, leads to innumerable difficulties. One of the most important is that the equality of communities is emphasized (Elshtain, 1994). Every community claim is legitimate, and it is impossible to adjudicate the claims of conflicting groups.

In order to formulate meaningful social policy however, we must be able to say that some claims (and thus communities) are more valid than others. Charles Taylor (in O'Neill, 1994) addresses this issue at the level of culture and says: "While it is clear that we must be open to learning something new from a different culture we must accept that we may learn more from some than from others. What could be more homogenizing than the demand that we must find all cultures to be of equal worth?" (p. 148) A critical postmodernism research approach permits such judgements to be made.

Critical postmodernism preserves the scepticism of postmodernism but tempers its radical relativism with reflection and historical analysis. This approach avoids both the totalizing narratives of conventional research on the one hand, and absolute cultural relativism on the other. It negotiates a path in between.

A critical postmodern approach to research also preserves researcher independence. Independence should be distinguished from neutrality and objectivity. For example, the researcher may or may not have sufficient critical distance from the phenomenon of study interest to produce credible study findings. That is for the reader to judge. Similarly, the researcher may or may not be supportive of the study

participants, their activities, or cause. Pace bias, this too is essentially beside the point.

Researcher independence, however, refers to the intellectual freedom to ask questions

and interpret findings in accordance with their chosen theoretical framework. Anything

less than this level of intellectual freedom is politics, not science.

The issue of representation in research is a serious one. To what extent can or

should the interpretations of those who are the subject of research really be separated

from the researcher's own interpretations? In the case of community based research,

who has the right to speak for the community? Tremendous practical and theoretical

difficulties loom in this realm. Still, it is important to remember that the desire to

reflect reality as it is seen is the quest shared by the community based researcher and

the multiple voices of community. At least there is this one commonality to serve as a

starting point in discussions about research and representation.

Finally, and despite the urgency of a continued dialogue on the issue of

representation and research, it seems doubtful that research in any form can achieve

major social and political change. Even case study research undertaken in the spirit of

cultural criticism, as this research aims to be, is quite inadequate. I agree with

Shakespeare (1996) when he says: "While it is possible to make the research process

more balanced, grandiose claims for its revolutionary potential seen to me to be over-

optimistic" (p. 118). We must not give up on research however. For at its best,

rigorous research generates new insights and opens up new avenues of possibility for

positive social change. But research in and of itself will not secure the requisite levels

of social change required. Something more is needed. In the final analysis, positive

225

social change requires public commitment and action.

## Three Problems for Social Policy

As this research has shown, a disjuncture between the ideal features expected and those features found to exist in communities can pose many problems for the implementation of community based projects. For purposes of social policy development however, there are several unique concerns. These concerns relate to the issues of community representation and participation and the purposeful use of community language. To be clear, these are not problems from a social constructivist or postmodern perspective because under neither framework is it possible to critically evaluate the competing claims of various communities. To do so, and thus generate useful social policy, a critical postmodern approach is required. Because social policy is concerned with improving conditions for people with disabilities, it must also be concerned that people with disabilities represent only a small minority of the population. Is it good social policy to ensure tangible benefits for people with disabilities, if the remainder are excluded? Is this justifiable on the basis of disabled people's relative disadvantage? The risk in not advocating on behalf of people with disabilities, and by extension, other powerless groups, is that the majority will not otherwise see to their needs. How do those responsible for social policy ultimately balance the needs of the few against those of the many? These are clearly very central questions for social policy aimed at community based initiatives. Henry Enns, Executive Director of DPI, says "the struggle of any minority group always involves

226

the issue of who decides what for whom" (undated, p. 10). This is clearly so. And furthermore, as Walzer (in Williams, 1991) succinctly puts it, is "to find ways of providing for needy members because of their neediness in a way that does not undermine their status as members of society" (p. 522). This has never been an easy task. Communities beyond the realm of disability undoubtedly confront this same dilemma.

While this research does not provide recommendations for direction in disability policy development, it has identified several major issues that the policy developer will confront. The first of these problems is related to community representation and participation. This is the matter of community suspicion. Despite the cloak of goodness, concern and inclusion that envelopes all discussions about community, we now know, how deeply suspicious communities can be of "new and improved" methods to solve longstanding and complicated community problems. While not opposed in principle to participation and empowerment, communities remain circumspect about the strategies undertaken to attain it. If empowerment, for example, means the transfer of knowledge and skills to improve the decision-making ability of people in the community, then in the IL and CBR context at least, communities have demonstrated a willingness to resist it. What the community is resisting are externally created plans of action, whether generated by disability activists or state rehabilitation planners. In both cases, community resistance is to the uninformed proclamations of a right way to improve the community.

Reflection upon the behaviour of the actual communities targeted by IL and

227

CBR initiatives has produced the realization that community members may view community organizing as manipulative. While a sense of community obligation may be present to some degree in many communities in the South, as traditional cultures and economies become increasingly developed, it is not unreasonable to assume these pressures will have a negative influence upon traditions of collective responsibility and communal allegiance. Failures of projects espousing community participation have increased community suspicion as well. In some situations, this has meant that while community participation has not been overtly rejected, it is covertly undermined. If the community is coerced into participation, the participation will be far from genuine.

Scott (1986) refers to this covert resistance as "everyday forms of resistance," and has called the overall technique, the "ordinary weapons" of relatively powerless groups. What Scott (1986) is referring to is "the footdragging, dissimulation, false-compliance, pilfering, feigned ignorance, slander, arson, sabotage, and so forth" (p. 6) that can have a major impact on village wide programs. In order to retain some sense of control over a life filled with powerlessness, risk, and uncertainty, community members may find the only avenue open to them is passive noncompliance and evasion. Disability experts have often expected communal concern to override individual desire. Except in unusual circumstances, it does not. This research confirms that just as self-advancement is ubiquitous in individuals, it is likewise true of their communities. Without a more critical perspective on central concepts such as community however, international disability will continue to misjudge the power of ideas to shape the understanding of the nature and behaviour of real communities, and lose sight of the

228

real patterns of human social interaction. If those responsible for social policy development wish to avoid the pitfalls encountered in the implementation of IL and CBR, then they will need to heed the international lessons of community representation and participation in disability.

The second challenge for social policy is imbedded in the strategic use of community language by outsiders. The pervasiveness of this problem cannot be overstated. In an era of reduced government expenditure on human services, the development of community based programs provides an excellent forum for this to occur. The talk or language about community may in reality disguise strong forces for a reduction, not an expansion, in the provision of local resources and supports. Collins and Green (1994) have identified a clear ideological shift from institutional to community thinking in the international health policy arena. These authors detail in very specific terms how the language of community, devolution and decentralization disguise a distinct trend toward the privatization and corporatization of health. And the effects can be untoward.

First, by simply withdrawing from service provision, loosely using the rhetoric of community responsibility and community ownership, a government can allow the private market to control provision of health services (Berry, 1988). The meeting of human need is then replaced by a market-driven philosophy and a goal of maximized profit. The terms community and consumer become synonymous.

Second, and because some communities are better resourced than others, a move to a community based approach simply reinforces pre-existing inequalities between

229

communities, frequently along class lines (Ife, 1995). Communities with more resources (natural, financial or human) are far more likely to provide higher levels of service, including those related to health and rehabilitation. Disadvantaged and powerless communities, on the other hand, may be further disadvantaged by being denied support from a strong central administration. They are not empowered by a move to community at all. In fact, the opposite happens. Denied strong central administration, the rhetoric of community appears progressive while reinforcing traditional conservative understandings of the family, privatization, government cut-backs, and historical class, gender and ethnic inequalities. International IL and CBR has been slow to acknowledge the fact that local inequalities may be perpetuated, not ameliorated, by community based initiatives. It is hardly surprising therefore, that some vocal disability critics have demonstrated a cynicism about community based disability models (Miles, 1994a). Until the field of international disability and rehabilitation recognizes the underlying structural inequalities linked to administrative structures, cultural traditions, and political contexts, efforts to dispense disability services and heighten the awareness of disability issues will be significantly undermined.

It is impossible to ignore the fact that national governments are reducing their commitment to the public sector. The decrease in overall financial resources for health for example, may portend a real shift toward community responsibility. Certainly in Canada, community health boards and regional health authorities are being assigned traditionally centralized health ministry duties. With respect to the health related needs

of people with disabilities, the power to determine needs and apportion benefits, is now increasingly in the community's hands. While the language of community emphasizes the legitimacy of this position, in practical terms, this practice implies a heightened community pressure to ensure that resources are not wasted. In turn, this will lead to an unavoidable scrutiny of personal behaviours (Cockerham, Abel & Luschen, 1993). In other words, those who control the flow of resources will be very interested in where the boundaries between communities are situated, and very interested in the extent to which individual health behaviours result in ill health. McLean (1995) has studied the history of healthy choices within the context of mental health and urges great caution with respect to these issues. Like many others, McLean is very concerned that the language of partnership, choice, and even empowerment, only maintains the status quo. McLean writes,

> By absorbing an antihegemonic concept into its own vocabulary, and including "empowerment" among its service approaches, the mental health service industry has inadvertently managed to transform a politically challenging concept into one it could safely control and promote. Within the dictates of the market relation, the ideal of freedom, so central to the concept of empowerment, is simply depoliticized as it becomes restricted to the exercise of limited choice. By establishing a relation based on dependence on the mental health system, "consumer empowerment" distorts the concept of political empowerment by defeating any possibility of producing a genuine alternative to the mental health system. (p. 1067)

In short, according to McLean, the influence of community language is so great that the social power imbedded in the concept can be manipulated to the degree that the idea is rendered completely innocuous politically.

231

### Theoretical Contributions

The ideology of CBR and IL is universal and totalizing. Each offers a definitive description of the disability problem and prescribes a proper path to its resolution. For CBR, the answer lies in efficient geographical dispersion of appropriate rehabilitation technologies; for IL, the answer rests in personal empowerment and local control. The language of community, perfused as it is with nostalgic images, has only obscured the meaning of community, the contested nature of real communities, and the function of the idea of community within ideology.     In the South, IL and CBR both suffer from the deficiencies of top-heavy bureaucracies, elite control, communication problems, personal power struggles, restrictive organizational mandates, a fragmented population of individuals and organizations interested in community disability but holding very different agendas, a society generally unsure of its commitment to special needs groups, and finally a heterogenous group of people with disabilities with diverse views on what constitutes appropriate disability services. Under such conditions, mobilizing for improvements in the situation of people with disabilities worldwide is an immense challenge. While both IL and CBR claim, at least in part, to have emancipated people with disabilities from the institution and repatriated them to their rightful place in the community, to what degree has this shift represented success?

For IL and CBR, community stands for hope -- hope that the predictability of the past can be effectively recaptured and used to alleviate current and future disability problems. But of course, the promise remains unfulfilled. There is no going back. In their efforts to mobilize interest, participation and commitment to disability activities,

232

proponents of IL and CBR have linked their mission to the positive features of an ideal form of traditional community that may or may not have anywhere existed. This has transpired to their peril. Neither IL or CBR have experienced optimal levels of success. This relates directly, this thesis research concludes, to their failure to appreciate and engage the complexity of this persuasive concept.

## New Directions for Social Theory

Has this research moved us any further with respect to community organizing and social theory? We can be sure of one thing, namely that a critical postmodern research approach has left open that possibility. This would not be so for the social constructivist or the postmodern researcher, committed as they are to a relativist position. The chosen methodology for this research can claim this social policy advantage. Preservation of critical reflection ensures that we move "beyond the immediate and self-referential" (Fisher & Kling, 1991, p. 79). This is a significant advantage because otherwise, the creation of community becomes "as important an accomplishment as the realization of political goals" (Shefner, 1995, p. 610). That is clearly unacceptable. We must therefore conclude, at least, that communities of choice are insufficient grounds upon which to claim societal benefits. In John Ralston Saul's (1995) terminology, these communities are not sufficiently *disinterested*. In *Unconscious Civilization*, Saul persuasively argues that while special interest groups are concerned for themselves, moral communities are concerned for the common good. Practically speaking, this means IL and CBR must be concerned with more than rights

233

and advocacy (IL) and service delivery (CBR) for people with disabilities. To be morally legitimate, they must scale the walls of their historical mandates and traditional constituencies and engage in broad-based, inclusive initiatives. It is this aspect of community that may provide the ultimate criterion for the determination of community legitimacy.

Research with respect to community and community organizing is moving in two major directions today, which reflect longstanding historical divisions between socialist and liberalist traditions. The spectrum of thought within the extremes of these positions is immense, but there are patterns to be discerned. There is a communitarian literature ranging from the socially conservative such as Etzioni (1993) and Selznick (1992), to the more the politically liberal Taylor (1989), Sandel (1982) and Walzer (1983). Moral and political theory owes much to scholars like Habermas (1984, 1987), and also Cohen (1983 & 1985) who has made the ambitious and important work of Habermas more broadly accessible. Gilligan (1982) and Benhabib (1992) have also provided moral philosophy a much needed feminist corrective in regard to its theorizing about community. Finally, new social movement theory has emerged as an attempt to revitalize community organizing theory. All of these theorists are committed to a deeper understanding of civil society, and for some, the development of a structure of ethics to inform social change.

New social movement theory is emerging as a particularly important influence on theorizing about community. With strong historical ties to Marxist thinking and the Frankfurt School, new social movement theory is expanding widely in both Northern

234

and Southern contexts and is developing its own distinctive literature (Boyte &

Riessman, 1986; Evans & Boyte, 1986; Fisher & Kling, 1993; Melucci, 1989;

Escobar & Alvarez, 1992; Morris & Mueller, 1992; Wignaraja, 1993). While

significant enthusiasm is building in this area, Shefner (1995) still reminds us of the

insights gained during decades of previous research. "In the obsession with novelty,"

Shefner writes, "many of the material bases of protest are forgotten in the search for

community roots" (Shefner, 1995, p. 596). Shefner's point and others' is that

strategies employed to address societal inequalities take new forms over time, but

underlying social forces that sustain inequalities do not (Fisher & Kling, 1994; Pilisuk,

McAllister & Rothman, 1996). If we are to understand social movements as purposive

political action, and not just autonomous expressions of cultural constituencies, then old

questions of strategy, organization and grievance must be re-engaged.

In addition to revisiting old theories of social change, another major task is to

discover the mechanisms by which "the creative energies of the people, particularly the

poor and the vulnerable" can be unleashed, for as Wignaraja (1993) correctly points

out, it is they who "must be the final arbiters of their lives" (p. 12). This is hardly a

new discovery. But it bears repeating that individuals affected by social policy

decisions must be involved in the process. Furthermore, this process must mean more

than the determination of community needs and the mechanisms to address them. It

must include a debate about who the community actually is. This is far from a trivial

matter, as this thesis research has shown. Not only is community affiliation

increasingly time-limited, issue-specific, and cut loose from physical location, the

235

fundamental basis for community membership is under debate. While greater attention

must be given to community claims, similar levels of energy must be devoted to

ensuring that barriers of exclusion are not created in the process. Naive calls for

community participation offer little in this regard. What we are speaking about here is

a fundamental recreation of a sense of public (Bellah, 1996; Fowler, 1991; Selznick,

1995). To really become a community requires a deep understanding of the way

participation and consensus making are intertwined, and a more fundamental

appreciation of the means by which participation contributes to countervailing power.

> What causes one to participate -- an outer or an inner authority or voice? And,
> in so doing, is the participant prompted by need, greed, insecurity, fear,
> interest, fame, power over others, or some other factors, or is there no motive
> or objective for the participant's caring, other than the inner necessity for one to
> relate to others a sensitive human being (Rahnema, 1993, p. 221)?

Genuine participation then, in the pursuit of morally legitimate community, poses a

tremendous challenge for civil society. Rahnema (1993) continues,

> To live that way requires, indeed, a tremendous energy, intelligence, and
> sensitivity, and above all, an unusual inner freedom, particularly in a world
> where the mediatized hegemony of authoritative and attractive concepts is
> systematically corrupting people's faculty of perception. It implies that one
> questions endlessly one's own motives, attitudes, beliefs, ways of life, habits,
> traditions, and thought processes. And to question is not to be pathologically
> skeptical about everything; it only means to be critically self-aware and yet
> passionately compassionate. By fully participating in the world, such a person
> becomes not only one's own change agent, but one who, by the same token,
> changes the world. (p. 223)

Critical reflection, freedom and personal conviction are essential factors in the

236

enterprise of positive social change. But other factors, including innovation and creativity, are important too as they open up theoretical space for addressing what Morris and Mueller (1992) have called the democratic deficit. Social space for citizen activity is precisely what Walzer (1994) calls for as well. Walzer (1994) claims that increasing opportunities for civil participation "is our best protection against the parochialism of the groups in which they participate" (p. 189). The unfortunate reality for contemporary community organizing is that despite shared characteristics and objectives, social protest has been fragmented into so many exclusive, and sometimes antagonistic components that "they tend to parallel rather than interact with each other" (Fisher & Kling, 1994, p. 15). This fragmentation can only be overcome by a reinvigoration of the notion of public coalitions. In this way, like-minded individuals and organizations can bring unity and power to resistance movements, thereby strengthening the fabric of civil society overall.

## Conclusion

The discussion of community and social theory could likely continue well beyond the point we have reached here. But, the critical examination of community in the context of IL and CBR has achieved its primary purpose. The complexity and persuasive power of the idea of community has been revealed. The thesis research has shown that IL and CBR conceive of and assert community status in different ways, despite the similar ways in which they use the word, and the way in which those actual groupings of people calling themselves communities behave. Like the terms

237

development and participation before it, community's referent is always to a good and just cause. Because participation and community are predetermined to be good, involving oneself in participatory community based activities are imbued with goodness too. In the case of IL and CBR, this has meant that proponents of these ideologies may have leapt forward prematurely to in their enthusiasm to deliver community based disability programs. When this is the case, methods of implementation assume the forefront, while the question of existing levels of interest in disability and the complexity of it all slips quietly aside. Importantly though, these forgotten issues are usually of utmost importance to the success of community based disability initiatives.

The examination of community has not been exhaustive. Not was it intended to be. But, the evidence presented in the context of international disability does range from that of the elite expert to that of the disadvantaged and powerless. The examples cross-cut North-South and lay-professional knowledge claims. And in addition, this analysis has captured the public and obvious representations of community, as well as the private and the hidden. As Day and Murdoch (1993) identify, there is significant power in this approach for it is at this interface between the local and the external "that the meaning and salience of community and locality becomes manifest" (p. 93). Yet, this is not to say that all of the research questions have been answered. There are many others. For example, does a movement's focus on community and community-building blunt a pragmatic political agenda? Can a focus on community mute diverse voices? Does an emphasis on autonomy lead to ideological rigidity or political intransigence? Does collective identity eventually become a public good, a cultural commodity

available to a much wider community than those working toward social change? Does

this commodification of the movement's identity in turn lessen its ability to define its

cause? When a community's symbols gain acceptance in popular culture, will its

associated problems fade in the public's consciousness without address?

This research has shown that while the theme of community, emphasizing as it

does local control, rights, roots, and empowering personal relationships, may at some

level be desirable, real and lasting social change is not possible in an economy or

society unwilling to meet human needs. In the case of disability specifically, Asch

(1986) for one is deeply sceptical about the prospects of populism (and its concomitant

celebration of community) empowering disabled people. Asch writes,

> Populism may get neighbourhoods more services and citizens a greater sense of
> personal control. Disability rights activists may change a few laws, reform
> certain service programs, and eventually bring their constituency nearer to the
> kind of life of the "average" citizen. Such reforms are valuable. Nonetheless,
> they leave basic social and economic arrangements untouched, because they are
> only intended to redistribute the national pie. If, in fact, all we do is get more
> of rotten pie, what do we have to eat (p. 226)?

Real life is a far cry from the warmth, support and goodness conjured up by a naive

reading of community, as this research confirms. Societal forces are substantial and

enduring, and they can be negative and injurious. When we confront the harshness of

society, what is our response? Do we retreat into the security of a more comforting

historical (or imaginary) past? Do we embrace comforting memories and pleasing

images in order to quell our anxieties about an uncertain future? Does this explain the

quest for community?

239

If this research has accomplished anything, it has been to reveal a considerable mystical strain in our yearning for community. Our quest for community seems to represent an orientation toward nature that is deeply loved. If its overwhelming prevalence in the international discourse of IL and CBR is any indication, it seems that the appeal of community is so great that its presence will not be dispensed with anytime soon. So, will the troubling aspects of community ever be sorted out? I believe there will be progress, but in the end we will fall short for the simple reason that in the final evaluation, community is either a *result* of individual choice, and burdened with the same risks as all other activities undertaken under uncertain circumstances, or, community *precedes* all choice, in the sense of a priori predisposing individuals to some loyalty or values. Bauman (1996), in his sophisticated treatment of community and human freedom, captures this sentiment exactly when he writes: "This dilemma signals a trade-off situation; the value acquired and cherished needs to be sacrificed in order to gain the value missed" (p. 87). Community probably implies a human longing for union that inevitably lies beyond our reach. This vision of human fate, and thus community, is perhaps a tragic one. But it is also the human condition.

# REFERENCES

Abraham, C., Panackel, J., & Thomas, M. (1994). Community based rehabilitation -- a comparison of rural and urban programmes. ACTIONAID Disability News (Bangalore, India), 5(2), 97-99.

Adair-Toteff, C. (1995). Ferdinand Tönnies: Utopian visionary. Sociological Theory, 13(1), 358-365.

Adisubroto, W. (1991, May). The role of mutual cooperation in rural Indonesian development. Paper presented at the ESCAP Training Course on Community Based Support Services for Disabled Persons, PPRBM Prof. Dr. Soeharso, Solo, Indonesia.

Agger, B. (1991). Critical theory, poststructuralism, postmodernism: Their sociological relevance. Annual Review of Sociology, 17, 105-131.

Aguirre, J. (1995). Independent living = capacity + aids [Editorial]. Helioscope, 4, 1-2.

Albrecht, G. (1992). The disability business: Rehabilitation in America. Newbury Park, CA: Sage.

Alexander, J. (1995). Modern, anti, post, neo. New Left Review, 210, 63-104.

Alinsky, S. (1969). Reveille for radicals. New York: Vintage Books.

Altheide, D., & Johnson, J. (1994). Criteria for assessing interpretive validity in qualitative research. In N. Denzin & Y. Lincoln (Eds.), Handbook of qualitative research (pp. 485-499). Thousand Oaks, CA: Sage.

Alvares, C. (1992). Science, development and violence: The revolt against modernity. New York: Oxford University Press.

Anderson, B. (1972). The idea of power in Javanese culture. In C. Holt (Ed.), Politics and culture in Indonesia. Ithaca, NY: Cornell University Press.

Anspach, R. (1979). From stigma to identity politics: Political activism among the physically disabled and former mental health patients. Social Science and Medicine, 13A, 765-773.

Armstrong, M. J. (1993). Disability self-help organizations in the developing

world: A case study from Malaysia. International Journal of Rehabilitation Research, 16, 185-194.

Asch, A. (1986). Will populism empower disabled people? In H. Boyte & F. Riessman (Eds.), The new populism: The politics of empowerment (pp. 213-228). Philadelphia: Temple University Press.

Atkinson, P. (1990). The ethnographic imagination: Textual constructions of reality. London: Routledge.

Balasundaram, P. (1994). Hello CBR. Goodbye CBR. We found a new friend. International League of Societies for Persons with Mental Handicaps News, 16, 12-13.

Balcazar, F., Mathews, R., Francisco, V., Fawcett, S., & Seekins, T. (1994). The empowerment process in four advocacy organizations of people with disabilities. Rehabilitation Psychology, 39, 189-203.

Banerji, B., Banerji, J., Banerjee, N., & Srivastav, L. (1992). Tin shed rehabilitation. CBR News, 10, 5.

Barnes, C. (1996). Theories of disability and the origins of the oppression of disabled people in western society. In L. Barton (Ed.), Disability and society: Emerging issues and insights (pp. 43-60). New York: Longman.

Batavia, A. (1993). Health care reform and people with disabilities. Health Affairs, Spring, 40-57.

Baum, F. (1995). Researching public health: Behind the qualitative-quantitative methodological debate. Social Science and Medicine, 40(4), 459-468.

Bauman, Z. (1996). On communitarians and human freedom. Theory, Culture & Society, 13(2), 79-90.

Bell, C., & & Newby, H. (1971). Community studies: An introduction to the sociology of the local community. London: George Allen and Unwin.

Bellah, R. (1996). Habits of the heart: Individualism and commitment in American life (2nd ed.). Berkeley, CA: University of California Press.

Benhabib, S. (1992). Situating the self: Gender, community and postmodernism in contemporary ethics. New York: Routledge.

242

Berger, B. (1988). Disenchanting the concept of community. Society, September/ October, 50-52.

Berry, L. (1988). The rhetoric of consumerism and the exclusion of community. Community Development Journal, 23, 266-272.

Biklen, D. (1988). The myth of clinical judgement. Journal of Social Issues, 44(1), 127-140.

Bogdan, R., Biklen, D., Shapiro, A., & Spelkoman, D. (1982). The disabled: Media's monster. Social Policy, 13(2), 32-35.

Boschen, K., & Krane, N. (1992). A history of independent living in Canada. Canadian Journal of Rehabilitation, 6(2), 79-88.

Boyte, H., & Riessman, F. (Eds.). (1986). The new populism: The politics of empowerment. Philadelphia: Temple University Press.

Brewer, J. & Hunter, A. (1989). Multimethod research: A synthesis of styles. Newbury Park, CA: Sage.

Brown, S. (1992). Creating a disability mythology. International Journal of Rehabilitation Research, 15, 227-233.

Brownlea, A. (1987). Participation: Myths, realities and prognosis. Social Science and Medicine, 25(6), 605-614.

Butchart, A., & Seedat, M. (1990). Within and without: Images of community and implications for South African psychology. Social Science and Medicine, 31(10), 1093-1102.

Cameron, C., & Gatewood, J. (1994). The authentic interior: Questing Gemeinschaft in post-industrial society. Human Organization, 53, 21-32.

Chermak, G. (1990). A global perspective on disability: A review of efforts to increase access and advance social integration for disabled persons. International Disabilities Studies, 12(3), 123-127.

Coburn, D., Torrance, G., & Kaufert, J. (1983). Medical dominance in Canada in historical perspective: The rise and fall of medicine? International Journal of Health Services, 13(13), 407-432.

Cockerham, W., Abel, T., & Luschen, G. (1993). Max Weber, formal rationality,

and health lifestyles. Sociology Quarterly, 34, 413-425.

Cocks, E. (1994). Encouraging a paradigm shift in services for people with disabilities (Social Research and Development Monograph No. 9). Perth, Western Australia: Edith Cowan University, Centre for the Development of Human Resources.

Cohen, J, (1983). Rethinking social movements. Berkeley Journal of Sociology, 28, 97-113.

Cohen, J, (1985). Strategy or identity: New theoretical paradigms and contemporary social movements. Social Research, 52(4), 663-716.

Collins, C., & Green, A. (1994). Decentralization and primary health care: Some negative implications in developing countries. International Journal of Health Services, 24, 459-475.

Condeluci, A. (1991). Interdependence: The route to community. Winter Park, FL: PMD Publishers Group.

Conrad, P., & Schneider, J. (1980). Deviance and medicalization: From badness to sickness. St. Louis, MO: C. V. Mosby.

Crawford, R. (1994). The boundaries of the self and the unhealthy other: Reflections on health, culture and aids. Social Science and Medicine, 38(10), 1347-1365.

Christenson, J., Fendley, K., & Robinson, J. (1989). Community development. In J. Christenson & J. Robinson (Eds.), Community development in perspective (pp. 1-25). Ames, IA: Iowa State University Press.

Christenson, J. & Robinson, J. (Eds.). (1989). Community development in perspective. Ames, IA: Iowa State University Press.

D'Aubin, A. (1991). The power of the pen: Empowering words. In Disabled People in International Development (pp. 12-15). Winnipeg, Canada: Council of Canadians with Disabilities.

Day, G., & Murdoch, J. (1993). Locality and community: Coming to terms with place. The Sociological Review, 4(1), 82-111.

Deegan, P. (1988). Recovery: The lived experience of rehabilitation. Psychosocial Rehabilitation Journal, 11(4), 11-19.

DeJong, G. (1979). Independent living: From social movement to analytic paradigm. Archives of Physical Medicine and Rehabilitation, 60, 435-446.

DeJong, G. (1993). Health care reform and disability: Affirming our commitment to community [The John Stanley Coulter lecture]. Archives of Physical Medicine and Rehabilitation, 74(10), 1017-1024.

Denzin, N. (1994). The art and politics of interpretation. In N. Denzin & Y. Lincoln (Eds.), Handbook of qualitative research (pp. 500-515). Thousand Oaks, CA: Sage.

Denzin, N., & Lincoln, Y. (Eds.). (1994). Handbook of qualitative research. Thousand Oaks, CA: Sage.

Derksen, J. (1980). The disabled consumer movement: Policy implications for rehabilitation service provision. Winnipeg, Canada: Council of Canadians with Disabilities.

Deschesne, M. (1995, March). Socio-cultural factors that could affect the implementation of CBR Programs in Indonesia: Interviews with the fieldworkers from Central Java and North Sulawesi. Kingston, Canada: International Centre for the Advancement of Community Based Rehabilitation.

DiGiacomo, S. (1992). Metaphor as illness: Postmodern dilemmas in the representation of body, mind and disorder. Medical Anthropology, 14, 109-137.

Disabled People's International (DPI). (1982). A Voice of Our Own: Proceedings of the 1st World Congress of DPI, November 30-December 4, 1981, Singapore. Winnipeg, Canada: Author.

DPI. (1987, January). DPI's Statement on Equalization of Opportunities. Winnipeg, Canada: Author.

DPI. (1992). Equalization of Opportunities: Proceedings of the 3rd World Congress of DPI, April 21-26, 1992, Vancouver. Winnipeg, Canada: Author.

DPI. (1993). The DPI Constitution: Preamble. Winnipeg, Canada: Author.

DPI. (1995). DPI promotional materials. Winnipeg, Canada: Author.

DPI. (undated). DPI Overview. Winnipeg, Canada: Author.

245

Dove, M. (Ed.). (1988). The real and imagined role of culture in development: Case studies from Indonesia. Honolulu: University of Hawaii Press.

Drake, R. (1992). Consumer participation: The voluntary sector and the concept of power. Disability, Handicap & Society, 7(3), 267-278.

Driedger, D. (1989). The last civil rights movement: Disabled Peoples' International. New York: St. Martin's Press.

Driedger, D. (1996). Emerging from the shadows: Women with disabilities organize. In D. Driedger, I. Feika & E. Girón Batres (Eds.), Across borders: Women with disabilities working together (pp. 10-25). Charlottetown, Canada: Gynergy Books.

Driedger, D., Feika, I., & Girón Batres, E. (Eds.) (1996). Across borders: Women with disabilities working together. Charlottetown, Canada: Gynergy Books.

Devlieger, P. (1995). Why disabled? The cultural understanding of physical disability in an African society. In B. Ingstad & S. Whyte (Eds.), Disability and culture (pp. 94-106). Berkeley, CA: University of California Press.

Eberly, S. (1988). Fairies and the folklore of disability: Changelings, hybrids and the solitary fairy. Folklore, 99, 58-77.

Ehrenreich, B. (1989). Fear of falling: The inner life of the middle class. New York: Pantheon.

Eldridge, P. (1984). The political role of community action groups in India and Indonesia: In search of a general theory. Alternatives, 10, 401-434.

Elshtain, B. (1994). Democracy on trial. Concord, Canada: Anansi.

Enns, H. (1982). The historical development of attitudes toward the handicapped: A framework for change. In Perspectives on Disability and the Helping Process (pp. 175-186). Winnipeg, Canada: Disabled People's International.

Epp, J. (1986). The Epp Report. Achieving health for all: A framework for health promotion. Ottawa, Canada: Health and Welfare Canada.

Escobar, A. (1992). Reflections on `development': Grassroots approaches and alternative politics in the third world. Futures, June, 411-436.

Escobar, A., & Alvarez, S. (Eds.). (1992). The making of social movements in
  Latin America: Identity, strategy and democracy Boulder, CO: Westview
  Press.

Esteva, G. (1985). Development: Metaphor, myth, threat. Development, 3, 78-79.

Etzioni, A. (1993). The spirit of community: The reinvention of American society.
  Toronto, Canada: Touchstone.

Etzioni, A. (1996). The responsive community: A communitarian perspective [1995
  Presidential Address]. American Sociological Review, 61, 1-11.

Evans, R. (1988). "We'll take care of it for you": Health care in the Canadian
  community. Daedalus, 117(4), 155-189.

Evans, S., & Boyte, H. (1986). Free spaces: The sources of democratic change in
  America. New York: Harper & Row.

Everett, B. (1994). Something is happening: The contemporary consumer and
  psychiatric survivor movement in historical context. Journal of Mind and
  Behaviour, 15(1), 55-70.

Ferguson, P. (1987). The social construction of mental retardation. Social Policy,
  18(1), 51-56.

Finkenflügel, H. (Ed.). (1993). The handicapped community: The relation between
  primary health care and community based rehabilitation. Amsterdam: VU
  University Press.

Fisher, S. (Ed.). (1993). Fighting back in Appalachia: Traditions of resistance and
  change. Philadelphia: Temple University Press.

Fisher, R., & Kling, J. (1994). Community organization and new social movement
  theory. Journal of Progressive Human Services, 5(2), 5-23.

Fisher, R. & Kling, J. (Eds.). (1993). Mobilizing the community: Local politics in
  the era of the global city. Newbury Park, CA: Sage.

Fisher, R., & Kling, J. (1991). Popular mobilization in the 1990s: Prospects for the
  new social movements. New Politics, 3, 71-84.

Foster, G. (1982) Community development and primary health care: Their
  conceptual similarities. Medical Anthropology, Summer, 183-195.

247

Foster, G. (1987). Bureaucratic aspects of international health agencies. Social Science and Medicine, 25, 1039-1048.

Foucault, M. (1965). Madness and civilization. New York: Vintage.

Fowler, R. (1991). The dance with community: The contemporary debate in American political thought. Lawrence, KS: University Press of Kansas.

Freire, P. (1971). Pedagogy of the oppressed. New York: Seabury Press.

Friedson, E. (1970a). Professional dominance. New York: Atherton Press.

Friedson, E. (1970b). Profession of medicine. New York: Dodd-Mead.

Gadacz, R. (1994). Rethinking disability: New structures, new relationships. Edmonton, Canada: University of Alberta Press.

Gallagher, E., & Subedi, J. (1992). Studying health in developing countries: A conceptually-informed research agenda. Central Issues in Anthropology, 10, 127-133.

Geertz, C. (1960). The religion of Java. Chicago: University of Chicago Press.

Geertz, H. (1961). The Javanese family. New York: Free Press of Glencoe.

Gilligan, C. (1982). In a different voice. Cambridge, MA: Harvard University Press.

Glaser, B., & Strauss, A. (1967). The discovery of grounded theory. Chicago: Aldine.

Goffman, E. (1961). Asylums. New York: Anchor Press.

Grace, V. (1991). The marketing of empowerment and the construction of the health consumer: A critique of health promotion. International Journal of Health Services, 21, 329-343.

Green, R. (1991). Politics, power and poverty: Health for all in 2000 in the Third World? Social Science and Medicine, 32(7), 745-755.

Greene, J., & McClintock, C. (1985). Triangulation in evaluation. Design and analysis issues. Evaluation Review, 9(5), 523-545.

248

Greenwood, J. (1985). Disability dilemmas and rehabilitation tensions: A twentieth century inheritance. Social Science and Medicine, 20(12), 1241-1252.

Gritzer, G., & Arluke, A. (1985). The making of rehabilitation: A political economy of medical specialization, 1890-1980. Los Angeles: University of California Press.

Grob, G. (1995). The paradox of the deinstitutionalization. Society, 32(5), 51-59.

Groce, N., & Zola, I. (1993). Multiculturalism, chronic illness, and disability. Pediatrics, 91(5) (Suppl.), 1048-1055.

Groch, S. (1994). Oppositional consciousness: Its manifestation and development. The case of people with disabilities. Sociological Inquiry, 64(4), 369-395.

Guba, E., & Lincoln, Y. (1994). Competing paradigms in qualitative research. In N. Denzin & Y. Lincoln (Eds.), Handbook of qualitative research (pp. 105-117). Thousand Oaks, CA: Sage.

Habermas, J. (1984). The theory of communicative action (Vol. 1). Boston: Beacon Press.

Habermas, J. (1987). The theory of communicative action (Vol. 2). Boston: Beacon Press.

Hahn, H. (1985). Towards a politics of disability. Social Science Journal, 22(4), 87-105.

Hahn, H. (1988). The politics of physical differences. Journal of Social Issues, 44(1), 39-47.

Haliman, A., & Williams, G. (1983). Can people move bureaucratic mountains? Developing primary health care in rural Indonesia. Social Science and Medicine, 20, 1241-1252.

Hancock, T. (1993). The evolution, impact and significance of the healthy cities/healthy communities movement. Journal of Public Health Policy, Spring, 5-18.

Harvey, D. (1990). Introduction. Sociological Perspectives, 33(1), 1-10.

Harvey, D. (1995). The condition of postmodernity. Oxford: Blackwell.

Harvey, L. (1990). Critical social research. London: Unwin Hyman.

249

Hawe. P. (1994). Capturing the meaning of 'community' in community intervention evaluation: Some contributions from community psychology. Health Promotion International, 9, 199-210.

Helander, E. (1993). Pride and prejudice: An introduction to community-based rehabilitation. New York: United Nations Development Programme.

Helander, E. (1995). CBR concept and principles -- a historical perspective. CBR Frontline Digest, II(2), 6.

Helander, E., Mendis, P., Nelson, G., & Goerdt, A. (1989). Training in the community for people with disabilities. Geneva: World Health Organization.

Heller, K. (1989). The return to community. American Journal of Community Psychology, 17(1), 1-15.

Henley, D. (1992). Nationalism and regionalism in a colonial context: Minahasa in the Dutch East Indies. Unpublished doctoral dissertation, Australian National University.

Henry, W. (1994). In defense of elitism. New York: Anchor/Doubleday.

Hillery, G. (1955). Definitions of community: Areas of agreement. Rural Sociology, 20, 111-123.

Hirsch. K. (1995). Culture and disability: The role of oral history. Oral History Review, 22(1), 1-27.

Holmes, G. (1993). The historical roots of the empowerment dilemma in vocational rehabilitation. Journal of Disability Policy Studies, 4, 1-20.

Hughes, R. (1994). Culture of complaint. New York: Time Warner.

Husveg, A. (1995). Community-based rehabilitation: Another viewpoint. International Rehabilitation Review, 46(3), 20.

Ife, J. (Ed.). (1995). Community development: Creating community alternatives -- vision, analysis, and practice. Sydney, Australia: Longman.

Ignatieff, M. (1994). Blood and belonging: Journeys into the new nationalism. New York: Farrar, Strauss & Giroux.

Illich, I. (1976). Medical nemesis. New York: Pantheon.

Illich, I., Zola, I., McKnight, J., Caplan, J., & Shaiken, H. (1977). Disabling professions. London: Marion Boyars.

Ingstad, B. (1990). The disabled person in the community: Social and cultural aspects. International Journal of Rehabilitation Research, 13, 187-194.

Ingstad, B. (1995). Public discourses on rehabilitation: From Norway to Botswana. In B. Ingstad & S. Whyte (Eds.), Disability and culture (pp. 174-195). Berkeley, CA: University of California Press.

Ingstad, B., & Whyte, S. (Eds.). (1995). Disability and culture. Berkeley, CA: University of California Press.

International Centre for the Advancement of Community Based Rehabilitation (ICACBR). (1990). Centre of Excellence for the Development of CBR Programs for the Physically Disabled. Queen's University, Kingston, Canada: Author.

ICACBR. (1993). ICACBR Demonstration Projects 1992-1993. Queen's University, Kingston, Canada: Author.

ICACBR. (1993, January). ICACBR Background. ICACBR Update, Vol. 1.1, 2.

ICACBR. (1993, September). An Indonesian Experience. ICACBR Update, Vol. 1.2, 6-7.

International Labour Organization/United Nations Educational Scientific and Cultural Organization/World Health Organization. (1994). Joint Position Paper on CBR. Geneva: Author.

International Rehabilitation Review. (1994). Denmark to support development of special education in Mongolia. International Rehabilitation Review, 45(1), 24-25.

Islam, A., & Wiltshire, R. (1994). Traditional health systems and public policy. Proceedings of an International Workshop, Ottawa, Canada, March 2-4, 1994. Ottawa, Canada: International Development Research Centre.

Israel, B., Checkoway, B., Schulz, A., & Zimmerman, M. (1994). Health education and community empowerment: Conceptualizing and measuring perceptions of individual, organizational, and community control. Health Education Quarterly, 21, 149-170.

251

Jacobs, J. (1992). Systems of survival: A dialogue on the moral foundations of commerce and politics. New York: Vintage Books.

Jewkes, R., & Murcott, A. (1996). Meanings of community. Social Science and Medicine, 43(4), 555-563.

Johnston, M., & Tjandrakusuma, H. (1982). Reaching the disabled. World Health Forum, 3(3), 307-310.

Jongbloed, L, & Crichton, A. (1990). A new definition of disability: Implications for rehabilitation practice and social policy. Canadian Journal of Occupational Therapy, 57(1), 32-38.

Kalangie, N. (1995, January). Sociocultural factors in planning and implementing community-based rehabilitation programs: Javanese and Minahasan cases. (Available from ICACBR, Queen's University, Kingston, Canada).

Kaseje, D., Spencer, H., & Sempebwa, E. (1987). Characteristics and functions of community health workers in Saradidi, Kenya. Annals of Tropical Medicine and Parasitology, 81(1), 56-66.

Kaufert, P., & Gilbert, P. (1986). Women, menopause and medicalization. Culture, Medicine and Psychiatry, 10(1), 7-21.

Keiffer, C. (1984). Citizen empowerment: A developmental perspective. In J. Rappaport & R. Hess, (Eds.), Studies in empowerment: Steps toward understanding and action. New York: Haworth Press.

Kellner, D. (1990). Critical theory and the crisis of social theory. Sociological Perspectives, 33(1), 11-33.

Kincheloe, J., & McLaren, P. (1994). Rethinking critical theory and qualitative research. In N. Denzin & Y. Lincoln (Eds.), Handbook of qualitative research (pp. 138-157). Thousand Oaks, CA: Sage.

Kingwell, M. (1996). Dreams of millennium: Report from a culture on the brink. Toronto, Canada: Viking/Penguin.

Kirshner, C. (1990). The politics of disability statistics: Who counts what and why. Disability Studies Quarterly, 10, 1-2.

Kisanji, J. (1995). Understanding CBR models. CBR News, 19, 5.

252

Koch, A. (1993). Rationality, romanticism and the individual: Max Weber's "modernism" and the confrontation with "modernity." Canadian Journal of Political Science, 26(1), 123-144.

Koentjaraningrat. (1985). Javanese culture. Institute of Southeast Asian Studies, Singapore: Oxford University Press.

Kothari, M., & Mehta, L. (1990). Violence in modern medicine. In A. Nandy (Ed.), Science, hegemony and violence (pp. 167-210). Tokyo: The United Nations University.

Krefting, L. (1990). Rigor in qualitative research: The assessment of trustworthiness. The American Journal of Occupational Therapy, 45(3), 214-222.

Krefting, D., Krefting, L., & Tjandrakusuma, H. (1993). Community based rehabilitation in Central Java. In Culture and disability. Berkeley, CA: University of California Press.

Krogh, K., & Petric, L. (1994). Choices, flexibility and control in community research. Ottawa, Canada: Canadian Association of Independent Living Centres.

Kugelmass, J. (1990). The Indonesian system of caring: Mental handicap and family adaptation in West Java. New York: World Rehabilitation Fund, International Exchange of Experts and Information in Rehabilitation.

Labonte, R. (1989). Community empowerment: The need for political analysis. Canadian Journal of Public Health, 80, 87-88.

Labonte, R. (1994). Health promotion and empowerment: Reflections on professional practice. Health Education Quarterly, 21(2), 253-268.

Labonte, R. (1996). The language of community development. Paper presented at Evaluating Participation in Community Development: Future Directions, October 4-6, 1996, ICACBR, Queen's University, Kingston, Canada.

Lagerkvist, B. (1992). Community-based rehabilitation -- outcome for the disabled in the Philippines and Zimbabwe. Disability and Rehabilitation, 14(1), 44-50.

Lalonde, M. (1974). A New Perspective on the Health of Canadians -- A Working Document. Ottawa, Canada: Ministry of Supply and Services.

Lang. R. (1995). Special or integrated. CBR News, 20, 5.

Lele, J. (1993). On the politics of community-based rehabilitation. Paper presented at Asia in the 1990s: Meeting and Making a New World, October 29-31, 1993, ICACBR, Queen's University, Kingston, Canada.

Lele, J., & Dalal, A. (1993). Partners for independence: Models that work. Paper presented at the First North American Regional Conference of Rehabilitation International, October 27-29, 1993, Atlanta, GA.

Liggett, H. (1988). Stars are not born: An interpretive approach to the politics of disability. Disability, Handicap & Society, 3(3), 263-275.

Lincoln, Y. (1992a). Sympathetic connections between qualitative methods and health research. Qualitative Health Research, 2(4), 375-391.

Lincoln, Y. (1992b). Fourth generation evaluation, the paradigm revolution and health promotion. Canadian Journal of Public Health, 83 (Suppl. 1), 6-10.

Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.

Lord, J., & Hutchison, P. (1993). The process of empowerment: Implications for theory and practice. Canadian Journal of Community Mental Health, 12, 5-22.

Lupton, D. (1992). Discourse analysis: A new methodology for understanding the ideologies of health and illness. Australian Journal of Public Health, 16(2), 145-150.

Lysack, C. (1992). Community based rehabilitation and volunteerism: An Indonesian experience with the motivation of volunteer workers. Unpublished master's thesis, Queen's University.

Lysack, C. (1995). Community participation and community-based rehabilitation: An Indonesian case study. Occupational Therapy International, 2(3), 149-165.

Lysack, C. (1996a). Critical reflections on the meaning of community. ACTIONAID Disability News (Bangalore, India), 7(2), 43-47.

Lysack, C. (1996b). IDEAS 2000 holds seminar on Asia-Pacific developments in independent living and CBR. Portfolio '96 (Annual progress report of the International Disability Exchanges and Studies Project), 5-14. New York: Rehabilitation International/World Institute on Disability.

Lysack, C. (1996c). Community disability projects: Common ground and critical challenges for CBR and disabled people's organizations, CBR Update (ICACBR Newsletter), 2, 2.

Lysack, C. (1996d). Is community based rehabilitation a good thing for people with disabilities [Special feature]? A Voice of Our Own (Council of Canadians with Disabilities Newsletter), 14(2), 4-7.

Lysack, C., & Kaufert, J. (1994a). Comparing the origins and ideologies of the independent living movement and community based rehabilitation. International Journal of Rehabilitation Research, 17(3), 231-240.

Lysack, C., & Kaufert, J. (1994b). Disabled consumers' perspectives on community based rehabilitation. Discussion paper prepared for Disabled People's International, Sydney, Australia, December 1994.

Lysack, C., & Kaufert, J. (1996). Some perspectives on the disabled consumers' movement and community based rehabilitation in developing countries. ACTIONAID Disability News (Bangalore, India), 7(1), 5-9.

Lysack, C., & Krefting, L. (1993). Community-based rehabilitation cadres: Their motivation for voluntarism. International Journal of Rehabilitation Research, 16, 133-141.

Lysack, C., & Krefting, L. (1994). Why do women volunteer? CBR News, 17, 5.

Lysack, C., Martinez, K., & Kaufert, J. (1996). The cultural construction of disability: Comparing the North American independent living movement and community based rehabilitation. Paper presented at the 95th Annual Meeting of the American Anthropology Association, November 20-24, 1996, San Francisco, CA.

Madan, T. (1987). Community involvement in health policy: Socio-structural and dynamic aspects of health beliefs. Social Science and Medicine, 25(6), 615-620.

Mai, U. (1989). Political elites in a Minahasan village, North Sulawesi, Indonesia. Sojourn, 4(1), 100-112.

Marglin, F., & Marglin, S. (1990). Dominating knowledge: Development, culture and resistance. Oxford: Clarendon Press.

Marshall, C., & Rossman, G. (1989). Designing qualitative research. Newbury Park, CA: Sage.

Marwick, A. (1995). Two approaches to historical study: The metaphysical (including `postmodernism') and the historical. Journal of Contemporary History, 30, 5-35.

Mason, A. (1993). Liberalism and the value of community. Canadian Journal of Philosophy, 23(2), 215-240.

May, R. (1950). The meaning of anxiety. New York: Roland Press.

McColl, M., & Paterson, J. (1995, September). Critical dimensions of community-based rehabilitation. Queen's University, Kingston, Canada: ICACBR.

McKinlay, J. (1993). The promotion of health through planned sociopolitical change: Challenges for research and policy. Social Science and Medicine, 36(2), 109-117.

McLean, A. (1995). Empowerment and the psychiatric consumer/ex-patient movement in the United States: Contradictions, crisis and change. Social Science and Medicine, 40(8), 1053-1071.

McKnight, J. (1987). Regenerating community. Social Policy, Winter, 54-58.

McKnight J. (1994). Community (A 3-part series beginning October 26, 1994). On L. Sinclair (host), Ideas. Toronto, Canada: Canadian Broadcasting Corporation Radio Canada programme.

Melucci, A. (1989). Nomads of the present: Social movements and individual needs in contemporary society. Philadelphia: Temple University Press.

Menon, P. (1984). Developing community-based rehabilitation services for the disabled by the primary health care approach. International Rehabilitation Medicine, 6, 64-66.

Miles, M. (1985). Where there is no rehab plan: A critique of the WHO scheme for community based rehabilitation. Unpublished manuscript. Peshawar, Pakistan.

Miles, M. (1993). Different ways of community-based rehabilitation. Tropical and Geographic Medicine, 45(5), 238-241.

Miles, M. (1994a). Three elephants on a bicycle. Unpublished critique of the ILO, UNESCO, WHO 1994 Joint Position Paper on CBR.

Miles, M. (1994b). Information based rehabilitation & research. Paper presented at CBR Symposium, Bangalore, India, December 1994.

Miles, M. (1994, November). What is community-based rehabilitation [Foreword]? International League of Societies for Persons with Mental Handicap News.

Miles, M. (1995). Disability in an eastern religious context: Historical perspectives. Disability & Society, 10(1), 49-69.

Miller, B., & Khan, S. (1986). Incorporating voluntarism into rural development in Bangladesh. Third World Planning Review, 8(2), 139-152.

Mitchell, R., Zhou, D., Lu, Y., & Watts, G. (1993). Community-based rehabilitation: Does it change community attitudes towards people with disability? Disability and Rehabilitation, 15(4), 179-183.

Momm, W., & König, A. (1989). Experiences and reflections on a new concept of service provision for disabled people. Geneva: ILO.

Morris, J. (1991). Pride against prejudice: Transforming attitudes towards disability. London: The Women's Press.

Morris, A., & Mueller, C. (Eds.). (1992). Frontiers in social movement theory. New Haven: Yale University Press.

Morrow, R. (1991). Toward a critical theory of methodology. Current Perspectives in Social Theory, 11, 197-228.

Morrow, R. (1994). Critical theory and methodology. (Contemporary Social Theory, Vol. 3). Thousand Oaks, CA: Sage.

Nanavatty, M. (1988). The community development movement in South East Asian countries: An Asian perspective. Community Development Journal, 23, 94-99.

Nandy, A. (Ed.). (1990). Science, hegemony and violence: A requiem for modernity. Tokyo: The United Nations University.

Navarro, V. (Ed.). (1974). Imperialism, health and medicine. New York: Baywood.

Nibert, D. (1995). The political economy of developmental disability. Critical Sociology, 21(1), 59-80.

Nichter, M. (1986). The primary health center as a social system: PHC, social status, and the issue of team-work in south Asia. Social Science and Medicine, 23(4), 347-355.

Nisbet, R. (1967). Community and power. New York: Oxford University Press.

Oliver, M. (1984). The politics of disability. Critical Social Policy, 4, 2(11), 21-32.

Oliver, M. (1990). The politics of disablement. London: Macmillan.

O'Neill, S. (1994). Morality, ethical life and the persistence of universalism. Theory, Culture & Society, 11, 129-149.

O'Toole, B. (1987). Community-based rehabilitation (CBR): Problems and possibilities. European Journal of Special Education, 2(3), 177-190.

Papanek, H. (1982). Implications of development for women in Indonesia: Research and policy implications. Women and Politics, 2(4), 67-87.

Park, P. (1993). What is participatory research? A theoretical and methodological approach. In P. Park (Ed.), Voices of Change: Participatory research in the United States and Canada (pp. 1-17). Toronto, Canada: University of Toronto Press.

Parnes, P., & Tjandrakusuma, H. (1993). CBR - Partnerships between existing and emerging projects: Lessons from Indonesia. Paper presented at Partners for Independence, the First North American Regional Conference of Rehabilitation International, October 27-29, 1993, Atlanta, GA.

Parpart, J. (1993). Who is the `other'?: A postmodern feminist critique of women and development theory and practice. Development and Change, 24, 439-464.

Parsons, T. (1951). The social system. Glencoe, IL: Free Press.

Pearson, D. (1995). Community and sociology. Society, 32(5), 44-50.

Peat, M. (1990). Community based rehabilitation: Development and structure. In Community based rehabilitation: International perspectives. Kingston, Canada: Queen's University/ICACBR.

Peat, M. (1991a). Community based rehabilitation: Development and structure (Part I). Clinical Rehabilitation, 3, 219-227.

Peat, M. (1991b). Community based rehabilitation: Development and structure (Part II). Clinical Rehabilitation, 5, 231-239.

Peat, M., & Boyce, W. (1993). Canadian community rehabilitation services: Challenges for the future. Canadian Journal of Rehabilitation, 6(4), 281-289.

Periquet, A. (1984). Community based rehabilitation services: The experience of Bacolod, Philippines and the Asia/Pacific region. New York: World Rehabilitation Fund, International Exchange of Experts and Information in Rehabilitation.

Periquet, A. (1989). Community-based rehabilitation in the Philippines. International Disability Studies, 11, 95-96.

Phillips, M. (1990). Damaged goods: Oral narratives of the experience of disability in American culture. Social Science and Medicine, 30(8), 849-857.

Pilisuk, M., McAllister, J., & Rothman, J. (1996). Coming together for action: The challenge of contemporary grassroots community organizing. Journal of Social Issues, 52(1), 15-37.

Poedjangga. (1991, May). The implementation of CBR programme related to the gotong royong activity. Paper presented at the ESCAP Training Course on Community Based Support Services for Disabled Persons, May 1991, PPRBM Prof. Dr. Soeharso, Solo, Indonesia.

Populin, E. (1995). The concept of community based rehabilitation: Reflexions on current status and future perspectives. NU News on Health Care in Developing Countries, 2, 4.

Pratkanis, A., & Turner, M. (1996). Persuasion and democracy: Strategies for increasing deliberative participation and enacting social change. Journal of Social Issues, 52(1), 187-205.

Punch, M. (1994). Politics and ethics in qualitative research. In N. Denzin & Y. Lincoln (Eds.), Handbook of qualitative research (pp. 83-97). Thousand Oaks, CA: Sage.

Purohit, G. (1990). In Community based rehabilitation: International perspectives. Kingston, Canada: Queen's University/ICACBR.

Rahnema, M. (1990). Participatory action research: The "last temptation of saint" development. Alternatives, 15(2), 199-226.

Rappaport, J. (1985). In praise of paradox: A social policy of empowerment over prevention. American Journal of Community Psychology, 81, 9(1), 1-25.

Rappaport, J. (1987). Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. American Journal of Community Psychology, 15, 121-144.

Ratcliffe, J., & Gonzalez-del-Valle, A. (1988). Rigor in health-related research: Toward an expanded conceptualization. International Journal of Health Services, 18(3), 361-392.

Rathwell, T. (1992). Realities of health for all by the year 2000. Social Science and Medicine, 35, 541-547.

Richardson, L. (1994). Writing: A method of inquiry. In N. Denzin & Y. Lincoln (Eds.), Handbook of qualitative research (pp. 516-529). Thousand Oaks, CA: Sage.

Rienks, A., & Iskandar, P. (1988). Shamans and cadres in rural Java. In M. Dove (Ed), The real and imagine role of culture in development: Case studies from Indonesia. Honolulu: University of Hawaii Press.

Rifkin, S. (1983). Primary health care in southeast Asia: Attitudes about community participation in community health programs. Social Science and Medicine, 17, 1489-1496.

Riger, S. (1993). What's wrong with empowerment. American Journal of Community Psychology, 21, 279-292.

Rissel, C. (1994). Empowerment: The holy grail of health promotion? Health Promotion International, 9, 39-45.

Roestam, K. (1988). Family welfare movement (pkk) in Indonesia and its achievement. Unpublished manuscript. Jakarta, Indonesia.

Rondinelli, D., Nellis, J., & Cheema, G. (1983). Decentralization in developing countries: A review of recent experience (World Bank staff working papers No. 581, Management and development series No. 8). Washington, DC: The World Bank.

Rosenau, P. (1992). Health politics meets post-modernism: Its meaning and implications for community health organizing. Journal of Health Politics, Policy and Law, 19(2), 303-333.

Rudkin, L. (1994). Dependence status and happiness with old age on Java. Gerontologist, 32(2), 217-223.

Ruiter, T., & Schulte Nordholt, H. (1989). The village revisited: Community and locality in Southeast Asia. Sojourn, 4(1), 127-134.

Sachs, W. (1992). The development dictionary: A guide to knowledge as power. New Jersey: Zed Books.

Sagan, C. (1995). The demon-haunted world: Science as a candle in the dark. Toronto, Canada: Random House.

Said, E. (1978). Orientalism. Toronto, Canada: Random House.

Sandel, M. (1982). Liberalism and the limits of justice. Cambridge: Cambridge University Press.

Sardar, Z. (1992). Terminator 2: Modernity, postmodernism and the `other.' Futures, June, 493-506.

Saul, J. (1995). The unconscious civilization. Concord, Canada: Anansi.

Schaffer, R. (1991). Balanced participation in development. Tropical Doctor, 21, 73-75.

Scheer, J., & Groce, N. (1988). Impairment as human constant: Cross-cultural and historical perspectives on variation. Journal of Social Issues, 44(1), 23-37.

Schlaff, C. (1993). From dependency to self-advocacy: Re-defining disability. The American Journal of Occupational Therapy, 47(10), 943-948.

Scotch, R. (1988). Disability as the basis of a social movement: Advocacy and the politics of definition. Journal of Social Issues, 44(1), 173-188.

Scotch, R. (1989). Politics and policy in the history of the disability rights movement. The Milbank Quarterly, 67 (Suppl. 2, Pt. 2), 380-400.

Scott, J. (1986). Everyday forms of peasant resistance. Journal of Peasant Studies, 13(2), 5-35.

Scull, A. (1990). Deinstitutionalization: Cycles of despair. Journal of Mind and Behaviour, 11(3/4), 301-312.

Sechrest, L., & Sidani, S. (1995). Quantitative and qualitative methods: Is there an alternative? Evaluation and Program Planning, 18(1), 77-87.

Selim, M. (1995). Conference-based or community-based. International Rehabilitation Review, 46(1/2), 22.

Selznick, P. (1992). The moral commonwealth: Social theory and the promise of community. Berkeley, CA: University of California Press.

Selznick, P. (1995). Thinking about community: Ten theses. Society, 32(5), 33-37.

Shahani, M. (1990). In Community based rehabilitation: International perspectives. Kingston, Canada: Queen's University/ICACBR.

Shakespeare, T. (1996). Rules of engagement: Doing disability research. Disability & Society, 11(1), 115-119.

Shefner, J. (1995). Moving in the wrong direction in social movement theory. Theory and Society, 24, 595-612.

Silverman, M., Ricci, E., & Gunter, M. (1990). Strategies for increasing the rigor of qualitative methods in evaluation of health care programmes. Evaluation Review, 14(1), 57-74.

Silvers, A. (1995). Reconciling equality to difference: Caring (f)or justice for people with disabilities. Hypatia, 10(1), 30-55.

Smaling, A. (1994). The pragmatic dimension: Paradigmatic and pragmatic aspects of choosing a qualitative or quantitative method. Quality & Quantity, 28, 233-249.

Soepangadi. (1986). Country status report: Policies and programmes: Prevention and rehabilitation of the disabled in Indonesia. Jakarta, Indonesia: Republic of Indonesia, Department of Social Affairs.

Solo CBR Workshop (1995). The future of CBR - Crucial issues. Report from the Rehabilitation International Asia Pacific Region Pre-Conference Workshop on CBR, September 7-10, 1995, Solo, Indonesia.

Stake, R. (1994). Case studies. In N. Denzin & Y. Lincoln (Eds.), Handbook of qualitative research (pp. 516-529). Thousand Oaks, CA: Sage.

262

Stevenson, H., & Burke, M. (1992). Bureaucratic logic in new social movement clothing: The limits of health promotion research. Canadian Journal of Public Health, 83 (Suppl. 1), 47-53.

Stoler, A. (1977). Class structure and female autonomy in rural Java. Signs, 3(1), 74-89.

Stone, L. (1986). Primary health care for whom? Village perspective from Nepal. Social Science and Medicine, 22(3), 293-302.

Stone, L. (1992). Cultural influences in community participation in health. Social Science and Medicine, 35, 409-417.

Stone, S. (1995). The myth of bodily perfection. Disability & Society, 10(4), 413-424.

Sui, D. (1994). GIS and urban studies: Positivism, post-positivism, and beyond. Urban Geography, 15(3), 258-278.

Susman, J. (1994). Disability, stigma and deviance. Social Science and Medicine, 38(1), 15-22.

Sutherland, A. (1981). Disabled we stand. London: Souvenir Press.

Sutopo, H. (1993). Report: Evaluation of community based rehabilitation implementation in Banjarnegara, Sukoharjo, Sragen, and Wonosobo Central Java, Indonesia. Yayasaan Indonesia Bejahtera (YIS) Indonesia in coordination with the University of Alberta, Canada.

Talle, A. (1995). A child is a child: Disability and equality among the Kenya Maasai. In B. Ingstad & S. Whyte (Eds.), Disability and culture (pp. 56-72). Berkeley, CA: University of California Press.

Taylor, C. (1989). Sources of the self: The making of modern identity. Cambridge: Cambridge University Press.

Taylor, C. (1991). The malaise of modernity. Concord, Canada: Anansi.

Parliament of Canada. (1981). Obstacles Report: Report of the Special Committee on the Disabled and the Handicapped. Ottawa, Canada: Author.

Tjandrakusuma, H., & Murti, B. (1992). The strategy for the dissemination of community based rehabilitation in Central Java. Paper presented at the National

Seminar on Community Based Rehabilitation and Disability, February, 1992, Dhaka, Bangladesh.

Tönnies, F. (1957). Community and Society (Translated and edited by C. P. Loomis). New York: Harper Torch Books.

United Nations (UN). (1983). World Programme of Action Concerning Disabled Persons. New York: Author.

UN. (1984). The Standard Rules on the Equalization of Opportunities for Persons with Disabilities. New York: Author.

UN. (1986). Disability: Situation, strategies and policies. United Nations Decade of Disabled Persons 1983-1992. New York: Author.

Valentine, F. (1994). The Canadian independent living movement: An historical overview. Ottawa, Canada: Canadian Association of Independent Living Centres (CAILC).

Valentine, F. & Vickers, J. (1997). Released from the yoke of paternalism and "charity": Citizenship and the rights of Canadians with disabilities. International Journal of Canadian Studies, to appear.

Vanneste, G. (1994). Singing in the rain: Demystifying community-based rehabilitation. Unpublished manuscript. (Available from Christoffel Blindenmission International, Butare, Rwanda).

Verbrugge, L., & Jette, A. (1994). The disablement process. Social Science and Medicine, 38(1), 1-14.

Voth, D., & Brewster, M. (1989). An overview of international community development. In J. Christenson & J. Robinson (Eds.), Community development in perspective (pp. 280-306). Ames, IA: Iowa State University Press.

Wallerstein, N. (1992). Powerlessness, empowerment and health: Implications for American Journal of Health Promotion, 6(3), 197-205.

Walt, G., Perera, M., & Heggenhoughen, K. (1989). Are large-scale volunteer community health workers programmes feasible? The case of Sri Lanka. Social Science and Medicine, 29(5), 599-608.

Walzer. M. (1983). Spheres of justice. Oxford: Blackwell.

Walzer. M. (1994). Multiculturalism and individualism. Dissent, Spring, 185-191.

Wang. C. (1992), Culture, meaning and disability: Injury prevention campaigns and the production of stigma. Social Science and Medicine, 35(9), 1093-1102.

Wendell, S. (1989) Toward a feminist theory of disability. Hypatia, 4(2), 104-124.

Werner, D. (1985). Where there is no doctor: A village health care handbook. Palo Alto, CA: The Hesperian Foundation.

Werner, D. (1988). Disabled village children. Palo Alto, CA: The Hesperian Foundation.

Werner, D. (1994). Strengthening the role of disabled persons in community based rehabilitation programs. Unpublished manuscript. Palo Alto, CA: Health Rights.

Westacott, K. (1995). The need for appropriate technology in CBR. Report from the ICTA Seminar on Appropriate Technology - an essential part of a CBR programme, September 12, 1995, Jakarta, Indonesia.

White, D. (1992). (De)-constructing continuity of care: The deinstitutionalization of support services for people with mental health problems. Canadian Journal of Community Mental Health, 11(1), 85-99.

Williams, G. (1983). The movement for independent living: An evaluation and critique. Social Science and Medicine, 17, 1003-1010.

Williams, G. (1991). Disablement and the ideological crisis in health care. Social Science and Medicine, 32(4), 517-524.

Williams, G. & Satoto. (1981). Sociopolitical constraints in primary health care: A case study from Java. World Health Forum, 2(2), 202-208.

Williams, L. (1996). Reaching rural areas. CBR News, 22, 5.

Wignaraja, P. (Ed.). (1993). Rethinking development and democracy. In New social movements in the South: Empowering the people (pp. 4-35). London: Zed Books.

Woelk, G. (1992). Cultural and structural influences in the creation of and participation in community health programmes. Social Science and Medicine, 35, 419-424.

Wood. P. (1989). Measuring the consequences of illness. World Health Statistics Quarterly, 42, 115-121.

Woodward, M. (1985). Healing and morality: A Javanese example. Social Science and Medicine, 21(9), 1007-1021.

World Institute on Disability. (1996). IDEAS 2000 Independent Living Survey: International Findings. Oakland, CA: Author.

World Health Organizations (WHO). (1975). Promotion of National Health Services Relating to Primary Health Care. Official Records No. 226, Part I, Resolutions and Decisions, Annexes.

WHO. (1977). Community involvement in primary health care: A study of the process of community motivation and continued participation. (Report for the 1977 UNICEF-WHO joint committee on health policy, 31 January-2 February). Geneva: Author.

WHO. (1978). Alma-Ata declaration on primary health care. Geneva: Author.

WHO. (1981). Disability prevention and rehabilitation. (Report of the WHO Expert Committee on Disability Prevention and Rehabilitation. Technical Report Series No. 668). Geneva: Author.

WHO. (1982). Community based rehabilitation. (Report of a WHO interregional consultation Columbo, Sri Lanka, 28 June-3 July). Geneva: Author.

WHO. (1991). Second Evaluation of Strategy for Health for All by the Year 2000. Regional Committee for Europe, Copenhagen.

WHO/Health and Welfare Canada/The Canadian Public Health Association. (1986). Ottawa Charter for Health Promotion. Canadian Journal of Public Health, 77(6), 425-430.

Yach, D. (1992). The use and value of qualitative methods in health research in developing countries. Social Science and Medicine, 35(4), 603-612.

Yin, R. (1994). Case study research (2nd ed.). Thousand Oaks, CA: Sage.

Young, I. (1990). The ideal of community and the politics of difference. In L. Nicholson (Ed.), Feminism and postmodernism (pp. 300-323). New York: Routledge.

Zimmerman, M. (1990). Taking aim on empowerment research: On the distinction between psychological and individual conceptions. American Journal of Community Psychology, 18, 169-177.

Zola, I. (1982). Missing pieces: A chronicle of living with a disability. Philadelphia: Temple University Press.

Zola, I. (1986). Depictions of disability: Metaphor, message and medium in the media. Social Science Journal, 22, 5-17.

Zola, I. (1991). The medicalization of aging and disability. Advances in Medical Sociology, 2, 299-315.

Zola, I. (1993). Self, identity and the naming question: Reflections on the language of disability. Social Science and Medicine, 36(2), 167-173.

## Appendix A    **PROFILE OF KEY INFORMANTS**

Independent Living:

North

- 5  disability activists
- 3  program managers
- 2  academics/researchers

South

- 3  disability activists
- 5  program managers
- 1  academics/researc hers

Community Based Rehabilitation:

North

- 7  academics/researchers
- 2  program managers

South

- 3  academics
- 5  program managers
- 2  recipients of CBR services

## Appendix B       GUIDING INTERVIEW SCHEDULE

1.   How did you become involved in the disability rights (community based rehabilitation) movement?

2.   Which concepts and principles do you see are key to the ideology of disability rights (community based rehabilitation)? In what way is the ideology of community based rehabilitation (the disability rights movement) similar?

3.   How would you describe the differences between these two movements?

4.   What does "community" mean to you?

5.   What does "empowerment" mean to you?

6.   How broad a sphere of influence do you believe the disability rights (community based rehabilitation) movement has in Southern (developing) countries?

7.   Why do people belong to the disability rights movement (community based rehabilitation) movement?

8.   What factors (personal, organizational, socio-cultural, political) do you believe are key in achieving successful community disability projects in Asia? Are these factors different in the North American context?

9.   How do you characterize the future of these two movements -- one of competition, or one of collaboration?

## Appendix C    INFORMATION SHEET AND CONSENT FORM

### (RE)QUESTING COMMUNITY:

### A Critical Analysis of Community in the Discourse of

### Disability Rights and Community Based Rehabilitation

Cathy Lysack
Department of Community Health Sciences
University of Manitoba

### What is this study about?

You are being asked to participate in a research project directed by Cathy Lysack from the Department of Community Health Sciences, University of Manitoba, Winnipeg, Canada.  This study will specifically inquire about your knowledge of the history of the disability rights movement and community based rehabilitation and their impact on the field of disability.  You will be asked questions about your participation in these movements, and your motivation to be involved in these projects.  You will be asked about the concept of community empowerment and how you see this concept relating to consumer developed disability services and professional rehabilitation services.

### What do I do if I participate in this study?

If you decide to take part in this study, you will be interviewed at a time and location of convenience to you.  The interview will take approximately 60 minutes to complete and you are free to withdraw your participation at any time.  You may also refuse to answer any particular questions you may wish to.  There is no physical or psychological risk to participation.

### What are the benefits of my participation?

We believe you have valuable information to share about disability, community empowerment, disability rights and community based rehabilitation.  Although you may not benefit directly from this study, the information you provide will help to clarify the factors contributing to disability rights as a social movement, and the relationship between local efforts of disabled consumers and more medically oriented professional

approaches to disability. These data will be used to assist in developing appropriate disability services, particularly through community based projects, both in Southern (developing) countries such as Indonesia, as well as in remote areas of northern Canada.

## Will information be kept confidential and secure?

All participants interviewed for this research may remain anonymous if they so wish. Prior to obtaining informed consent, the purpose of the study will be explained and participation will be requested. Anonymity will be offered at this time.

Views with respect to anonymity may change throughout the course of the study, however. Therefore, several steps will be taken to recheck participants' wishes with respect to anonymity. First, a copy of the interview transcripts or notes will be provided to each participant and review and revision for will be encouraged. At this time, interview data will be rechecked for both accuracy and propriety. Second, given that the numbers of individuals within the international disability rights and community based rehabilitation movements are relatively small, if a significant number of study participants request anonymity, study findings will be presented as blended case studies, an approach that will ensure that individuals will not be identifiable to others within these organizations.

Prior to completion of the final draft of the PhD thesis and publication of study findings then, all comments and quotations directly attributable to any one study participant, and its context, will be provided in writing to the originating party so that he/she may amend or withdraw these remarks. The source's preference will be final with respect to changes of memory or insistence on non-attribution.

Throughout the course of the study, the researcher will maintain all consent forms, data, and data analysis in a secured, limited access room on the research site. Data will be stored in locked files and will be available to the principal researcher only. Data will not be used for any other purpose than this study and publication of findings resulting from this PhD research. No data will be disclosed to any third party for any other purpose without participant permission.

## Can I refuse to participate?

Participation in this study is completely voluntary. You may refuse to answer any question during the course of this interview. You may withdraw from this study at any time. You will not receive any financial remuneration for your participation.

If at any time you have further questions or concerns, you may contact the Principal Researcher, Cathy Lysack, or her PhD Supervisor, Dr. Joseph Kaufert, at the Department of Community Health Sciences at the University of Manitoba, Winnipeg, Canada. While Ms. Lysack is in Indonesia and the Solomon Islands, you may also contact the Directors of the disability projects sponsoring this research. (The Director provided you with this research Information Sheet).

By signing this consent form, I am indicating that I agree to participate in this study.*
In addition, I voluntarily authorize the use of my interview answers for:

- Education of disability workers, volunteers and/or rehabilitation professionals.
- Written material prepared for scholarly publication.

I am aware that this consent is a voluntary contribution in the interest of education and research.

_____        _____
Signature of Participant            Date

I have carefully explained to the participant the nature of the above research study. I certify that to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

_____        _____
Signature of Researcher             Date

_____        _____
Signature of Witness                Date

*       All study participants will receive a copy of the Information Sheet and Consent Form.

272