

THE ORIGINS AND HISTORY
OF DISABLED PEOPLES' INTERNATIONAL (DPI),
1945-1985

by

Diane Lynn Driedger

A thesis
presented to the University of Manitoba
in partial fulfillment of the
requirements for the degree of
Master of Arts
in
Faculty of Graduate Studies
History

Winnipeg, Manitoba

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ABSTRACT

This thesis discusses the origins and history of Disabled Peoples' International (DPI) for the period 1945-1985. DPI is an international self-help organization of people with various disabilities: mental, emotional and physical. Generally, nondisabled rehabilitation professionals, parents and others have tended to speak for and make decisions for people with disabilities. In contrast, DPI is an international voice of disabled people with member organizations in fifty-one countries as of 1985. It believes that disabled people themselves best know their own needs and aspirations and thus they should be involved in policy-making about their lives. DPI also asserts that disabled people have the same rights as all other citizens to fully participate in society in areas such as employment, the family, sexuality, political processes, and in religious and cultural life. While disabled people's organizations had existed at the local, national and international levels since 1945, DPI is the first international organization to include people with all types of disabilities. DPI has consultative status with the United Nations Economic and Social Council and other international bodies.

This thesis is based on primary and secondary materials, which include personal interviews with actors in the history of DPI. The social movement theory of Armand L. Mauss is employed to interpret DPI's development. The impact of DPI on disabled people around the world is also examined. The thesis concludes that DPI had a limited impact on grassroots disabled people. But, according to Mauss' social movement theory, it would appear that DPI was in its peak stage of development as an organization in 1985. Thus it had all the tools at its disposal to further the situation of disabled people around the world in the future.

TO DISABLED PEOPLE AND THEIR ALLIES IN THE SELF-HELP MOVEMENT EVERYWHERE

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PREFACE

Many people do not consider the history of disabled people to be very important. I discovered this while working on my thesis. Generally, the history of Disabled Peoples' International (DPI), an organization that embodies the struggle of disabled people, was not regarded as real history. I have been told that I should have been studying in the Social Work, Sociology or Medical faculties where "the problems of disabled people belong." But I argue that disabled people have a history, and that this should be written about and reflected upon. People with disabilities are not merely clients, patients or deviants to be dealt with in the fields of social work, medicine and sociology. Disabled people's history and their struggle for participation are starting to be recognized by society at large. This thesis, I hope, will serve to promote awareness of the goals and abilities of disabled people. Furthermore, it is important for disabled people to know their own history, just as it has been so crucial for all oppressed groups--black people, colonized peoples, women, and others--to learn about themselves.

I decided to write this thesis after I participated in the formation of DPI in 1981-82. I was a volunteer with the Mennonite Central Committee seconded to help organize the Founding Congress of DPI. I continued to work part-time with DPI while researching this thesis. I chose the topic because of my interest in social movements and how they bring about change. Disabled people have been one of the last minority groups to organize for their rights.

This thesis represents a segment of disabled people's history. This is an account of how disabled people built an international organization to represent themselves and to demand their rights as citizens of the world. I hope it will be a useful tool for disabled persons to reflect on the past struggle and to formulate strategies for the future.

INTRODUCTION

Disabled people are organizing all over the world. Organizations composed entirely of persons with various disabilities--physical, mental and emotional--have sprung up in one hundred countries since the mid-1970's. Disabled people have come to a realization that their societies were built without their input and participation. One of the results of this realization was the coming together of disabled people in Singapore in 1981 to form Disabled Peoples' International (DPI). DPI's mandate is to be the voice of disabled people. Furthermore, it believes that disabled people should be integrated into society and participate with the same rights as everyone else. DPI holds that one voice of all disabled people has more strength than each disability group speaking out separately on its own concerns. It has been granted consultative status with the United Nations, the United Nations Educational, Scientific, and Cultural Organization (UNESCO), and the International Labour Organization. While local, national and regional organizations have existed since 1945, DPI is the first successful effort of disabled people to create a united voice at the international level. This thesis will explore the history of DPI and its antecedents during the period 1945-1985.

DPI was formed to express the views of the 10% of the world's population who were disabled in one way or another. There were over 500 million disabled people worldwide in 1985.¹ Disabled people have a physical, men-

¹ World Health Organization, "World-wide Estimates of the Magnitude of the Disability Problem, Its Causes and Future Trends," quoted in E. Helander, P. Mendis and G. Nelson, Training the Disabled in the Community: An Experimental Manual on Rehabilitation and Disability Prevention for Developing Countries, (Geneva: World Health Organization, 1980), p. P-7.

tal, emotional, or sensory impairment, and their "handicap is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical or social barriers."²

In the 1980's, the majority of disabled persons, 80%, resided in the developing world--Africa, Asia, the Middle East, Latin America and the Caribbean. In some countries the incidence of disability due to malnutrition and communicable diseases was estimated at 20% of the population.³ Disabled people were generally poor people in the developed and developing worlds. This was due to lack of opportunities to work and participate in the mainstream of society. DPI affirmed that disabled people wanted to work and live in the community like nondisabled people. This view has arisen out disabled people's experiences since 1945.

By the 1960's and 1970's, people with disabilities began to question society's definition of them as odd and abnormal or as so-called cripples. They rejected the tendency of sociologists, social workers, and doctors to label them as deviants, clients and patients. They became aware that society's attitudes towards them were a handicap. These attitudes were that disabled people should be shut away from able-bodied society. Disabled people reminded everyone that all people were mortal and vulnerable to physical and mental disabilities. Furthermore, because disabled people had been warehoused in institutions and shut away in parental homes, they had no input into the building of society's streets, buildings, sidewalks and workplaces. Many disabled people could not participate fully in soci-

² Disabled Peoples' International, "DPI Constitution," 1983, p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

³ United Nations, World Program of Action Concerning Disabled Persons, (New York: United Nations, 1983), p. 13.

ety because they could not even enter most buildings. There were stairs, or narrow doorways where wheelchair users could not enter. If mobility-impaired people could not enter buildings, they could not attend university, hold down a job, or find a place to live outside an institution. Without education and income, disabled people could not become independent and enter the mainstream of society.

Disabled people, realizing these things, ceased blaming themselves for their limitations. They had internalized the attitudes of able-bodied society towards them.⁴ They began to see themselves as powerful and beautiful people. They had something to contribute to society. But, generally, society has viewed people with disabilities as a separate group, different from so-called normal people.

Writing about disabled people abounds and it appears in many different genres. Professionals in the areas of psychology, sociology, medicine and social work write about disabled persons as patients and subjects of study. Popular authors tell personal stories about disabled people who overcame their misfortunes and triumphed in life. Other literature focusses on the social situation of disabled people and proposes solutions. Mostly nondisabled people have written these accounts. While a few disabled people have written about themselves, they are often representing merely themselves. They do not recount the story of all of their sisters and brothers. But a new area of literature has opened up in the last ten

⁴ Paulo Freire, Pedagogy of the Oppressed (New York: The Seabury Press, 1970), pp. 60 and 50. Through Freire's theory of "conscientization" a person realizes that he/she can transform the world and is not merely a passive, mute being as society sees the oppressed person. Once oppressed people can name their oppression and where it originates, they can move on to change their life situation.

years. Disabled people are starting to write about themselves as a collective body of people and to propose solutions for the barriers to equality in their lives. Moreover, this literature does not only reflect the opinions and observations of a single author. It is representative of the philosophies and views of a mass of disabled persons, who have united into self-help organizations. It reflects disabled people's push for their full participation and equality in society.

First, especially since the end of World War II, professionals began to study and postulate about disabled persons. Returning war veterans who became disabled in the war and survivors of the polio epidemics of the 1940's and 1950's were rehabilitated with new medical techniques and began to live longer. Everything about their lives became the subject of professional investigation. Professionals often view disabled people as individuals with "problems." Disabled people's lack of participation in society is due to their disability, according to them. For example, medical professionals write about the physical rehabilitation techniques needed for different disabling conditions; and they discuss how disabling conditions affect disabled people's everyday physical functioning in society. How disabled people eat, sleep, talk, move around and cope emotionally with their physical "problem" is discussed.⁵

⁵ The following are some examples of this literature: Norman R. Bernstein, "Chronic Illness and Impairment," Psychiatric Clinics of North America 2 (Aug., 1971):331-346; Barney M. Dlin, Abraham Perlman and Evelyn Ringold, "Psychosexual Response to Ileostomy and Colostomy," American Journal of Psychiatry 126 (Sept., 1969):374-381; C. Murray Parkes and M.N. Napier, "Psychiatric sequelae of amputation," British Journal of Hospital Medicine (Nov., 1970):610-614.

On the other hand, some sociologists, psychologists and social workers write about how disabled people are viewed by society and how disabled persons participate in society. The following are examples of some of these works.

Sociologist Erving Goffman examines how society views people with physical defects and how this affects disabled people. In Stigma: Notes on the Management of Spoiled Identity, Goffman claims that society classifies disabled persons as "deviants." They cannot conform to the "normal" physical standards of society.⁶ In Asylums, Goffman studied institutions and discovered that institutions were run in many ways to benefit psychiatrists and care-giving staff. In mental institutions the staff expected obedience and a willingness to be in that setting. Often patients have been committed involuntarily by relatives and doctors. He also explains that when society has problems with someone who does not fit in socially, it institutionalizes them. In order to be declared well and released a person must bow to the system:

To get out of the hospital, or to ease life within it, they must show acceptance of the place accorded them, and the place accorded to them is to support the occupational role of those who appear to force this bargain. This self-alienating moral servitude, which perhaps helps to account for some inmates becoming mentally confused, is achieved by invoking the great tradition of the expert servicing relation, especially its radical variety.⁷

In both books Goffman describes society's attitudes towards disabled people, and how this affects their participation in society.

⁶ Erving Goffman, Stigma: Notes on the Management of Spoiled Identity (Englewood Cliffs, New Jersey: Prentice-Hall, 1963).

⁷ Erving Goffman, Asylums: Essays on the Social Situation of Mental Patients and Other Inmates (Chicago: Aldine Pub. Co., 1961), p. 386.

Indeed, many recent professional works, while studying disabled people as objects to be acted upon, are beginning to recognize that the social and physical environment handicaps disabled people. Physical barriers such as stairs handicap a person. It is not a wheelchair user's fault that he/she cannot climb those stairs. Marlett, Gall and Wight-Felske recognize this.⁸ They discuss how the service system is attempting to minimize the handicapping affects of the environment.

On the other hand, Wolfensberger prescribes "normalization" as the means to integrate mentally handicapped people into society.⁹ Normalization, he explains, is a process that professionals should use to integrate mentally disabled persons. They should have the chance to be "normal" like everyone else, as far as possible.

Another recent body of literature addresses the social and physical situations of disabled people. This literature suggests policy changes on the part of governments and social service agencies and changes in society's attitudes. The Canadian Government has published studies on the status of disabled persons.¹⁰ It has also issued a report on how to integrate disabled persons more fully into Canadian society.¹¹ Other organizations,

⁸ Nancy J. Marlett, Robert S. Gall and Aileen Wight-Felske, eds., Dialogue on Disability: A Canadian Perspective, Vol. 1: The Service System (Calgary: The University of Calgary Press, 1984).

⁹ Wolf Wolfensberger, Normalization: The principle of normalization in human services (Toronto: National Institute on Mental Retardation, 1972).

¹⁰ Health and Welfare Canada, Disabled Persons in Canada (Ottawa: Minister of Supply and Services Canada, 1980).

¹¹ Special Parliamentary Committee on the Handicapped and Disabled, Obstacles, The Third Report (Ottawa: Minister of Supply and Services Canada, 1981).

such as the Swedish Institute, have published similar studies.¹² Still other works focus on the history of barriers to disabled people's participation in society. Lenihan, Bowe, and Benderley discuss the history of different disability groups and their treatment in society.¹³

A recent body of work has focussed specifically on the social and physical barriers facing women with disabilities. Matthews, Fine and Asch, Browne et al., and Campling all discuss the status of disabled women in their respective countries.¹⁴ The majority of these books were written by women with disabilities.

Another area of work that is relatively small, but growing, is the church and persons with disabilities. Involving disabled persons in the church has become an important issue in the last five years in many denominations. Ohsberg's and Neufeldt's books deal with some of the issues.¹⁵

¹² Barbro and Folke Carlsson, Social Welfare and Handicap Policy in Sweden (Stockholm: The Swedish Institute, ca. 1981).

¹³ John Lenihan, "Disabled Americans: A History," Performance XXVII (Nov./Dec. 1976-Jan. 1977):1-72; Frank Bowe, Handicapping America: Barriers to Disabled People (New York: Harper and Row, 1978); Beryl Lief Benderley, Dancing Without Music: Deafness in America (New York: Anchor Press/Doubleday, 1980).

¹⁴ Gwyneth Ferguson Matthews, Voices From the Shadows: Women With Disabilities Speak Out (Toronto: Women's Educational Press, 1983); Michelle Fine and Adrienne Asch, "Disabled Women: Sexism Without the Pedestal," Journal of Sociology and Social Welfare VIII (July, 1981):233-248; Susan E. Browne, Debra Connors and Nanci Stern, eds., With the Power of Each Breath: A Disabled Women's Anthology (Pittsburgh: Cleis Press, 1986); Jo Campling, Images of Ourselves: Women with Disabilities Talking (London: Routledge and Kegan Paul, 1981).

¹⁵ H. Oliver Ohsberg, The Church and Persons With Handicaps (Scottsdale, Penn.: Herald Press, 1982); Aldred H. Neufeldt, ed., Celebrating Differences (Newton, Kansas: Faith and Life Press, 1984).

Another body of literature about disabled persons is the popular life stories of super disabled people who overcome their disabilities to do normal things like other people: for example, graduate from university or hold a job. This writing is of three types. First, disabled people tell their individual life stories. Cleland and King recite how they overcame their disabilities to contribute to society.¹⁶ Second, family members write about their experiences with disabled individuals. Killilea, Linedecker, and Glick discuss how their families coped with disabled members.¹⁷ Some authors, such as Schaefer, deviate from the super disabled person genre.¹⁸ Schaefer, rather than exclaiming about how wonderful her daughter is, even though she's disabled, discusses the problem that society has with accepting disabled people as human beings. She suggests ways to integrate disabled persons into everyday life.

The third type of super disabled persons literature is written by third parties who are capturing a human interest story. Valens and Harry tell the stories of brave disabled women: for example, Helen Keller and Jill Kinmont.¹⁹ Campbell tells of Colonel Baker, a blind man who founded the

¹⁶ Max Cleland, Strong at the Broken Places (Lincoln, Virginia: Chosen Books, 1980); Mike King, The Mike King Story (Intercourse, Penn.: Good Books, 1985).

¹⁷ Marie Killilea, Karen (Englewood Cliffs, New Jersey: Prentice-Hall Inc., 1952); Clifford Linedecker, with Michael and Maureen Ryan, Kerry: Agent Orange and an American Family (New York: St. Martin's Press, 1982); Ferne Pellman Glick, Breaking Silence: A Family Grows with Deafness (Scottsdale, Penn., Kitchener, Ont.: Herald Press, 1982).

¹⁸ Nicola Schaefer, Does She Know She's There? (Toronto: Fitzhenry & Whiteside, 1978).

¹⁹ Evans G. Valens, A Long Way Up: The Story of Jill Kinmont (New York: Harper & Row, 1966); Gerard Harry, Man's Miracle: The Story of Helen Keller and Her European Sisters (New York: Doubleday, Page and Co., 1913).

Canadian National Institute for the Blind.²⁰ Kleinfeld and McLean, profile disabled people who are successful, but their works also discuss the need for society to change in its attitudes.²¹ And they discuss the lack of accessibility for disabled people to transportation, jobs and buildings.

People involved in disabled people's self-help organizations have just begun to write about social attitudes. Finkelstein and Enns, write about society's attitudes towards disabled people and how they have interacted with disabled people's growing demand for change.²² They argue that since the early 1970's, disabled people have organized their own groups to represent themselves. Furthermore, they cite environmental and attitudinal barriers as the reasons for disabled persons' lack of participation, not their disabilities. Society, however, still views people with disabilities as sick, helpless patients who need to be cared for. They assert that disabled people's organizations are working to inform society about its attitudes and to help integrate disabled persons into the mainstream of life.

²⁰ Marjorie Wilkins Campbell, No Compromise: The Story of Colonel Baker and the CNIB (Toronto: McClelland and Stewart Ltd., 1965).

²¹ Sonny Kleinfeld, The Hidden Minority: A Profile of Handicapped Americans (Boston: Little, Brown & Co., 1979); D. John McLean, "Henry Enns Doing His Bit," Caliper XII (Sept., 1983): 14-18.

²² Victor Finkelstein, Attitudes and Disabled People: Issues for Discussion, No. 5 (New York: World Rehabilitation Fund, 1980); Henry Enns, "Canadian Society and Disabled People: Issues for Discussion," Canada's Mental Health 40 (Dec., 1981): 14-17; Henry Enns, "The Historical Development of Attitudes Toward the Handicapped: A Framework for Change," in Treating Families With Special Needs, eds. David S. Freeman and Barry Trute (Ottawa: Canadian Association of Social Workers, 1981).

Three branches of the disabled people's movement have emerged since 1970: the independent living movement, consumer organizations, and self-help groups. DeJong, and Crewe and Zola have written about the theory of independent living and the specific programs that an Independent Living Centre operates.²³ Independent living is disabled people living and participating in the community like everyone else. Disabled people themselves control the boards of Independent Living Centres, which are organizations to help them set up the services they need to live in the community. Disabled persons with more severe disabilities require services such as attendant care, or a helper to assist in personal care. Crewe and Zola's book discusses how to set up and implement services. Driedger and D'Aubin and the Independent Living Resource Centre discuss the history of the independent living movement in the United States and especially in Canada.²⁴ Independent living centres also publish their own articles and books for the users of their services, such as Richert's housing manual and Hummel and Gilpatrick's peer support manual.²⁵

²³ Gerben DeJong, "Independent Living: From Social Movement to Analytic Paradigm," Archives of Physical Medicine and Rehabilitation 60 (Oct., 1979):435-446; Nancy M. Crewe and Irving Kenneth Zola, Independent Living for Physically Disabled People (San Francisco: Jossey-Bass Publishers, 1983).

²⁴ Diane Driedger and April D'Aubin, "So You Want to Start an Independent Living Centre? A Winnipeg Case Study," Caliper XL (Dec., 1985):14-16; Independent Living Resource Centre, Independent Living for Persons with Disabilities in Canada, A Study Commissioned by the Secretariat on the Status of Disabled Persons, Dept. of the Secretary of State, Minister Responsible for the Status of Disabled Persons (Winnipeg: Independent Living Resource Centre, Inc., 1985).

²⁵ Val Regehr Richert, Moving In...A Housing Manual (Winnipeg: Independent Living Resource Centre, 1985); Barbara Hummel and Athonette Gilpatrick, Peer Support Training Manual (Wisconsin: Access to Independence, Inc., 1984).

Unlike independent living centers, consumer organizations of disabled people generally do not provide services. They monitor existing services provided by governments and non-profit rehabilitation organizations. And they believe that organizations should be multi-disability. They hold that all disability groups speaking together have a stronger impact than each group speaking separately. There is one voice for government and the public to hear, composed of 10% of the population. Consumer organizations are a Western world phenomenon. Derksen, writing as a disabled person involved in consumer organizations, outlines the philosophical underpinnings of the consumer movement.²⁶ Rehabilitation professionals have decided for disabled people in the past. Now, however, people, through their organizations, monitor the quality of their own services, such as rehabilitation, transportation, housing and employment. As citizens, disabled persons have rights to services that enhance a lifestyle of independent living.

Simpson builds on the independent living philosophy and explains the organizational structure and role consumer organizations play in Canadian society.²⁷ Bowe, et al., discuss the process of building coalitions of disabled persons' organizations in the US to lobby for rights.²⁸ Enns writes about the changes that these organizations have helped bring about.²⁹ Ross gives a media account of these relatively new organizations

²⁶ Jim Derksen, The Disabled Consumer Movement: Policy Implications for Rehabilitation Service Provision (Winnipeg: Coalition of Provincial Organizations of the Handicapped [COPOH], 1980).

²⁷ Allan J. Simpson, Consumer Groups: Their Organization and Function (Winnipeg: COPOH, 1980).

²⁸ F.G. Bowe, J.E. Jacoby, L.D. Wisemen, Coalition Building (Washington, D.C.: American Coalition of Citizens With Disabilities [ACCD], 1978).

²⁹ Enns, "Canadian Society and Disabled People."

and their philosophy and function in Canadian society.³⁰ Driedger writes a short history of the Canadian organization on its tenth anniversary, in 1986.³¹

The consumer movement also publishes conference reports and policy statements on different issues. The American Coalition of Citizens With Disabilities has published policy manuals on various issues.³² The Canadian Coalition of Provincial Organizations of the Handicapped has published several books as well.³³

Independent Living Centers sometimes influence governmental policies for all disabled people in their area (depending on the center), while consumer organizations do not provide services. But the third segment of the disabled persons' movement both influences governments and agencies, and provides services where they are needed. Self-help organizations of disabled people have emerged all over the world since the mid-1970's. In the developing world, where there were no independent living centers, disabled people formed self-help organizations to pressure governments and to provide services such as rehabilitation, technical aids (wheelchairs, braces, crutches and white canes), housing and employment. Miller, et

³⁰ Val Ross, "Demanding Access for All," Maclean's, April 20, 1981.

³¹ Diane Driedger, "Speaking for Ourselves: A History of COPOH on its 10th Anniversary," in Coalition of Provincial Organizations of the Handicapped 1985-86 Annual Report (Winnipeg: COPOH, 1986).

³² Bowe, Coalition Building.

³³ Jim Derksen, ed., Report on a Open National Employment Conference (Winnipeg: COPOH, 1978); COPOH, Getting to Know COPOH (Winnipeg: COPOH, 1985); Derek Fudge and Patty Holmes, Together for Social Change: Employing Disabled Canadians (Ottawa: National Union of Provincial Government Employees and COPOH, 1983); April D'Aubin, ed., Defining the Parameters of Independent Living (Winnipeg: COPOH, 1986).

al., and Miller and Chadderdon, edited collections of articles and speeches by leaders in self-help groups.³⁴

There are several histories on national self-help organizations. Edwards writes about the founding of People First in the United States, Sweden and Canada in the mid-1970's.³⁵ This is the international organization run by mentally handicapped people. There is also a booklet in Swedish that outlines the history of the Swedish blind people's movement, 1889-1964.³⁶ Heath writes about the first meeting of the Australian national organization, in 1983.³⁷ Carnes provides some histories of the British and Swedish movements in his work.³⁸ He compares these movements to the US disabled people's movement. He concludes that British and Swedish organizations are ahead of US organizations. His measuring stick is whether the government has a formal mechanism for consulting with disabled people's organizations on policies that affect them, and whether the move-

³⁴ Kathleen Miller, Linda M. Chadderdon and Barbara Duncan, eds., Participation of People With Disabilities: International Perspectives (Michigan: University Centre for International Rehabilitation, Michigan State University, 1981); Kathleen S. Miller and Linda M. Chadderdon, eds., A Voice of Our Own, Proceedings of the First World Congress of Disabled Peoples' International, Nov. 30-Dec. 4, 1981, Singapore (East Lansing, Michigan: University Center for International Rehabilitation, Michigan State University, 1981).

³⁵ Jean Parker Edwards, We Are People First: Our handicaps are secondary (Portland, Oregon: EDNICK, 1982).

³⁶ De Blindas Forening. De Blindas Forening 75 ar (Stockholm: De Blindas Forening, 1964).

³⁷ Jeff Heath, ed., 'When Others Speak for You, You Lose': Proceedings of the First National Assembly of Disabled Peoples' International (Australia), Melbourne, 1983 (Adelaide: The South Australian Chapter of Disabled Peoples' International, Inc., 1983).

³⁸ G.D. Carnes, Social Justice Through Handicapped Power: Perspectives from England and Sweden (Michigan: University Centre for International Rehabilitation, Michigan State University, 1982).

ment has a large and well-organized national organization. Finally, he also asserts that the US movement is not activist and has not attempted to bring about change. But he provides no historical evidence to back up these assertions.

Several pieces have been written about Disabled Peoples' International (DPI), the multi-disability umbrella organization of disabled peoples' groups, both consumer and self-help. Driedger has written two articles on DPI. The first, entitled "From Winnipeg to Singapore" documents the beginnings of DPI, from June 1980 to December 1981.³⁹ The second paper, "Disabled Peoples' International (DPI): An International Self-Help Organization," defines DPI and gives an overview of its beginnings and accomplishments.⁴⁰ Kathleen Miller writes several pieces on the beginnings of DPI as well.⁴¹ These pieces are in no way comprehensive historical studies, and they are written for a popular audience. And, while DPI has pub-

³⁹ Diane Driedger, "From Winnipeg to Singapore," in A Voice of Our Own, Proceedings of the First World Congress of Disabled Peoples' International, Nov. 30 - Dec. 4, 1981, Singapore, eds. Kathleen S. Miller and Linda M. Chadderdon (Michigan: University Centre for International Rehabilitation, Michigan State University, 1982).

⁴⁰ Diane Driedger, "Disabled Peoples' International (DPI): An International Self-Help Organization," forthcoming in Mobility in the Global Village: A State-of-the-Art Review of Access to Transportation for Elderly and Disabled Persons, ed. Transport Canada (Ottawa: Minister of Supply and Services Canada, 1986).

⁴¹ Kathleen S. Miller, "Disabled People Coming Together Internationally," in Participation of People With Disabilities: An International Perspective, eds. Kathleen S. Miller, Linda M. Chadderdon and Barbara Duncan (Michigan: University Centre for International Rehabilitation, Michigan State University, 1981); Kathleen S. Miller, "Around the Congress" and "A Chorus of Voices," in A Voice of Our Own, Proceedings of the First World Congress of Disabled Peoples' International, Nov. 30-Dec. 4, 1981, Singapore, eds. Kathleen S. Miller and Linda M. Chadderdon (Michigan: University Center for International Rehabilitation, Michigan State University, 1982).

lished several reports and books concerning its conferences, it has not documented its history either.⁴² Thus, while many works exist about disabled people as clients, patients, and objects of study and marvel, relatively few authors are disabled persons, or allies of the disabled peoples' movement. While it is true that disabled people within the movement have begun to write about themselves, their contributions often are not written as histories or well-researched.

Works written about and by disabled people are important to consider for this thesis. But, social movement theory put forward by sociologists can provide a framework to understand the organizational history of Disabled Peoples' International and the future directions it could take. First, Turner explains the reasons for the development of a social movement concerned with bringing about change: "A significant movement becomes possible when there is a revision in the manner in which a substantial group of people, looking at some misfortune, sees it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable to society."⁴³ Thus, a movement is formed when a group of people stop petitioning others for relief of their conditions and instead

⁴² Miller and Chadderdon, A Voice of Our Own Diane Driedger, The Winds of Change: Partners in Development, Proceedings of the Disabled Peoples' International (DPI) International Symposium on Development, 1-5 October 1984, Kingston, Jamaica (Winnipeg: DPI [Canada], Inc., 1985); Jeff Heath, ed., The Adelaide Experience: Report of the First Asia/Pacific Regional Convention of Disabled Peoples' International, Nov., 1984 (Adelaide: Disabled Peoples' International (Australia), Inc., 1984); Jeff Heath, ed., Developing Leaders: Report of Disabled Peoples' International Leadership Training Course, Adelaide, 1984 (Adelaide: Disabled Peoples' International (Australia), Inc., 1984); Yukiko Oka, ed., The Engines are Ready, Let's Go! Report of DPI Asia/Pacific Leadership Training Seminar, April 20-24, 1983 (Japan: DPI Asia/Pacific Regional Council, 1983).

⁴³ Ralph H. Turner, "The theme of contemporary social movements," The British Journal of Sociology (Dec., 1969):391.

demand amelioration of conditions as a right.

In addition, Zurcher and Snow examine the membership and organization of social movements.⁴⁴ Most importantly, they discuss the process of movements becoming organizations. They write: "Organization is necessary if a movement is to make any headway in its goal-attainment efforts."⁴⁵ They go on, though, to state that organization can lead to acquiescence and thus frustrate the attainment of goals. They conclude that, "the problem is not organization per se, but organizations that fail to develop and maintain a sense of enthusiasm and anticipation."⁴⁶ Thus, organization does not work against social movement goals, but organization without passion leads to stagnation. A dialectical tension between enthusiasm and idealism on one hand, and bureaucratism and pragmatism on the other is present.

Turner and Killian, on the other hand, discuss the life cycle of social movements. They explain that, "the life cycle is a way of organizing our knowledge about movements so as to permit prediction of forthcoming events."⁴⁷ Indeed, this model can be useful in analyzing the organizational life of DPI. The authors provide three stages of development. In the first there is general and unfocussed unrest in a population. In the second stage the reasons for unrest are focussed toward what should be changed. In the third stage, called "formal organization," the movement

⁴⁴ Louis A. Zurcher and David A. Snow, "Collective Behavior: Social Movements," in Social Psychology: Sociological Perspectives, eds. Morris Rosenberg and Ralph H. Turner (New York: Basic Books, Inc., Pub., 1981):447-82.

⁴⁵ Ibid., p. 478.

⁴⁶ Ibid.

⁴⁷ Ralph H. Turner and Lewis M. Killian, Collective Behavior, 2nd. ed. (Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1972), p. 253.

becomes a disciplined organization with goals and strategies.

While Zurcher and Snow, and Turner and Killian prove helpful to studying DPI, the work of Armand Mauss is the most useful for this thesis. First, he discusses how society defines reality and social problems. He holds that there is a consensual reality, or set of beliefs, that most people in society can agree on. But when those beliefs fall short of fulfilling the expectations of different interest groups "social problems" are defined:

When, however, this consensual reality, or common stock of knowledge, fails to 'deliver the goods,' or to make possible the solution of everyday problems, then people will begin to question it and will be open to new constructions of reality being offered by special interest groups."⁴⁸

Mauss then explains that social movements or interest groups arise and they redefine a situation in society as a social problem. The movement then influences the public's view of reality. According to Mauss, there are two types of consensual reality: informal and formal. Informal consensual reality is found in folklore, myths and anecdotes. It is a truth that is commonly understood in society, such as the idea that the growth of youth violence in society is an example of the loss of respect of youth for property and their elders. But in the case of disabled people, Mauss' concept of formal consensual reality is most important to consider.

Formal consensual reality is defined by organizations, institutions or people that are considered authorities. Examples of formal consensual reality are scientific and statistical studies. In the case of disabled people this would be the reality proposed by medical and social work pro-

⁴⁸ Armand L. Mauss, Social Problems and Social Movements (Philadelphia: J.B. Lippincott Company, 1975), p. 8.

professionals--the experts on disability. The public generally believes them because they hold the truth through science and medical rehabilitation knowledge. The disabled people's movement questioned these professionals' definition of reality for them, which was the "medical model." The medical model holds that disabled people are sick and must spend their whole lives getting well. According to Jim Derksen, a Canadian disabled activist, this sick role casts a disabled person into a dependent and passive role. He describes the effects of this stereotype as follows:

The disabled person is allowed less self-determination than what would normally be available to adults in his society, the disabled person is usually segregated from the participating majority in a treatment or recovery setting, he is made to feel lacking or defeated as he is most often unable to meet the chief responsibility given him of becoming well or able-bodied since most disabilities are permanent in nature.⁴⁹

Disabled people began to reject this medical definition of themselves after World War II. They started to define themselves as citizens of the world with the same rights as everyone else. It was not their fault that they could not climb stairs or read print. The inaccessible environment, that society had built, handicapped them. Thus, in the post-1945 world disabled people set out to redefine their situation for medical and social work professionals and the public. Mauss' concept of a group redefining its situation will be referred to throughout this thesis.

Second, Mauss also discusses factors that cause people to create and join social movements. A group that society defines as "subordinate" finds itself in a position where it has "rising expectations." It compares what it has to others in terms of money, status, power or possessions. It believes that it is also entitled to those things. Disabled

⁴⁹ Derksen, The Disabled Consumer Movement, p. 5.

people, having become more physically mobile, better educated and more independent after World War II, believed that they were citizens with the same rights as everyone else in society. Thus, when a group's rising expectations are frustrated by society, the group experiences "relative deprivation." There are five kinds of relative deprivation according to Mauss: economic, social, ethical, physical and psychological. Mauss emphasizes that "it is important to remember that his [the "subordinate" member] 'deprivation' in any case is defined by his own perceptions and is likely to be relative to time, place and situation."⁵⁰

Mauss also outlines the concept of "resource management" which movements use to mobilize successfully for change. Two of the most important resources are the leadership and the membership. If these two become successfully mobilized for action there will be committed volunteers to build the movement. Other important resources in mobilization are ideology and strategies and tactics. The ideology or philosophy of the movement must be appealing to the members: "These beliefs must be capable of providing a satisfactory explanation to members and prospective members concerning the causes of the problem and the steps that must be taken to solve it."⁵¹ In addition, strategies, the movement's plans, and the tactics, the means of carrying out the plans, are important to social movements: "...mobilization involves a repertory of successful strategies and tactics, which will help build membership, influence politicians or raise money."⁵² The kinds of tactics movements employ are lobbying, fund-rais-

⁵⁰ Mauss, Social Problems as Social Movements, p. 17.

⁵¹ Ibid., p. 56.

⁵² Ibid.

ing, seeking alliances and speaking in the media. This thesis will discuss how successfully DPI mobilized resources for change.

Mauss then discusses the leadership needed at different stages in social movements. Mauss claims that most movement leadership comes from the middle class and from people in professions where they can speak out more freely. Such people are teachers, lawyers, writers and other intellectuals. He discusses different kinds of leadership: charismatic, rational-legal and traditional. Charismatic leaders usually inspire and theorize for a movement in its beginning stages. Rational-legal leaders are usually salaried staff and people in positions in the hierarchy of the formal organization.⁵³ Traditional leadership is the handing down of power and position through the generations. The succession of kings and queens is a good example of this kind of leadership. Traditional leadership will not be discussed in the history of DPI, as it is not generally relevant for social movements. Traditional leadership takes time to develop and most social movements are short-lived.⁵⁴ This thesis will discuss whether Mauss' other forms of leadership exist in the short history of DPI.

Finally, Mauss' life cycle agrees with Turner and Killian, but he goes one step further in his analysis. He discusses the demise of organizations, thus completing the life cycle. Mauss explains the "incipiency" stage of unfocussed discontent, the "coalescence of people around a movement, the eventual "institutionalization," or stabilizing of a movement, and then discusses the "fragmentation" and eventual "demise" of social movement organizations. The incipiency stage is characterized by an unfo-

⁵³ Mauss, pp. 52-55.

⁵⁴ Ibid., p. 54.

cussed, unorganized approach to oppression. There is no membership or leadership in a movement at that point. The next stage, coalescence, is entered when a group of people start formal organizations with leaders and a membership to address that which they define to be oppressing them. Then, a social movement moves on to the institutionalization stage. This is the peak of the movement. It becomes well-known through the media. It has a membership, leaders and monetary resources. It lobbies for legislative and policy changes in society. Ultimately, legislation is enacted to address the changes the social movement is seeking. Finally, the movement begins to fragment and eventually fades away leaving behind a legacy of legislation and attitudinal changes. This thesis will employ Mauss' social movement theory to help interpret the development of Disabled Peoples' International as part of its discussion and conclusions. Indeed, in particular, his social movement life cycle can prove important in illuminating where DPI has been and its ultimate fate.

Disabled people all over the world have formed their own local and national organizations to carry out their strategies for change. DPI is the international manifestation of disabled people demanding integration into society. This thesis is based on interviews with disabled people involved in the movement. It is also based on reports, letters, and documents written by disabled people themselves. This thesis will provide the background for the period 1945-1980, and the founding and subsequent history of DPI, 1980-1985. Finally, Mauss' social movement theory will be used to help analyze the development of DPI.

Chapter I

POST WORLD WAR II DEVELOPMENTS, 1945-1980

A. TECHNOLOGICAL CHANGES

At the turn of the twentieth century, most disabled people were hidden from public view. In developed countries they were often housed in institutions for the so-called crippled, and asylums for the so-called mentally incompetent and deranged. In the developing nations (in Africa, Asia, the Middle East, Latin America and the Caribbean) families hid their disabled members in their homes. Their countries could not afford to build large institutions. Generally, the world viewed disabled people as unproductive burdens. Persons with mental illness were often viewed as possessed by demons.

The two World Wars began to change the lives of disabled people. After World War I many young men did not survive their disabling conditions, especially spinal cord injuries. The technology to rehabilitate these persons was not yet available. It was in the wake of World War II that industrialized countries began to improve medical rehabilitation techniques. These methods were soon available to the whole population. Young people with spinal cord injuries began to live longer.¹ Many disabled people be-

¹ Irving Kenneth Zola, "Helping One Another: A Speculative History of the Self-Help Movement," Archives of Physical and Medical Rehabilitation 60 (Oct., 1979):453; Diane Driedger, "The Struggle for Legitimacy: A History of the Coalition of Provincial Organizations of the Handicapped (COPOH)," in Dialogue on Disability: Vol. II, ed. Aileen Wight-Felske

came more mobile as better wheelchairs and prosthetics (artificial limbs) were developed. It was after World War II as well that the World Veterans Federation was established in 1950. It formed a rehabilitation department in 1952 to deal with the physical rehabilitation and integration of disabled veterans into society.²

In addition to a growing population of young people with spinal cord injuries, many young people and children became disabled due to the polio epidemics of the early 1950's in the Western world.³ With improved rehabilitation techniques and machines such as the iron lung, many people survived the epidemics. Some were quite severely disabled and relied on respirators and electric wheelchairs.

In addition, children were born disabled due to thalidomide, the anti-morning sickness drug of the late 1950's and early 1960's.⁴ Finally, the disabled war veterans of the Vietnam War joined the ranks of young disabled persons.

Thus, in the post-World War II Western world, many disabled young people began to live longer. And they had more mobility through improved technical aids. These young persons, greater in numbers than ever before, were generally not content to be locked away in institutions and nursing

(Calgary: University of Calgary Press, 1987, forthcoming), p. 2.

² Sven Ekroos, Vice President of Disabled War Veterans Association in Finland, Representative of World Veterans Federation, "Address to the DPI Seminar in Turku, Finland," August 1983, p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

³ Health and Welfare Canada, Disabled Persons in Canada (Ottawa: Minister of Supply and Services Canada, 1980), p. 21.

⁴ Ibid.

homes for the so-called crippled. After all, they had their whole lives in front of them.

B. THE REHABILITATION PROFESSIONS

The post-World War II era marked the rapid expansion of the rehabilitation professions. Institutions arose linked to the medical procedures needed to rehabilitate people physically. Disabled people were seen to have suffered tragedies and as unable to care for themselves. They needed care, and institutions were places for this. Disabled people were seen as passive, needing others to do things for them. They were segregated from the rest of society in care-giving institutions.⁵ Medical professionals defined disabled people as sick people who spent their lives trying to get well. This has served to influence society's view of disabled people. It provided a rationale for excluding them from participation in society.⁶ Since they were sick, they did not have to accept responsibility in everyday life; disabled people were already too busy getting well.

Separate schools, housing and special services were established to care for disabled persons. Thus, nondisabled people had few opportunities to interact with disabled people as human beings with aspirations, emotions, and feelings like themselves. The public saw disabled persons as those who needed a helping hand. They needed money for medical research to be cured. People watched telethons for these medical causes and gave money out of pity for these permanently sick people. They also gave out of

⁵ Victor Finkelstein, Attitudes and Disabled People: Issues for Discussion, No. 5 (New York: World Rehabilitation Fund, 1980), p. 10.

⁶ Henry Enns, "The Historical Development of Attitudes Toward the Handicapped: A Framework for Change," in Treating Families With Special Needs, eds. David S. Freeman and Barry Trute (Ottawa: Canadian Association of Social Workers, 1981), pp. 178-179.

fear. They did not want to become disabled like that, so these diseases and injuries must be cured. The public believed that normal life ended when one became disabled.

C. PARENTS AND FRIENDS ORGANIZE

In the 1950's, many parents, friends, and other interested people realized that disabled young people needed services, such as specialized education (often separate schools were set up because disabled children could not climb the stairs of the public school) and activities to occupy themselves. They wanted disabled people to live productive lives. Organizations of parents, friends, and in some cases rehabilitation professionals sprang up in most Western countries. Ultimately international organizations were formed composed of national non-profit organizations interested in the prevention of disability and the integration into society of people with one disability or another.

All of these international organizations were uni-disability (one disability) in focus. Few of them made concerted efforts to incorporate disabled people themselves in the membership, let alone the decision-making functions of the organizations.⁷ In 1953, the Council of World Organi-

⁷ These organizations were formed throughout the 1950's, '60's and early '70's. The following were examples of such organizations. Epilepsy International was incorporated in 1977, and was a union of two world organizations--the International League Against Epilepsy and the International Bureau for Epilepsy. (Epilepsy International, "Comprehensive Planning for Epilepsy 1982-1986," 1982, in author's possession). The International Cerebral Palsy Society was founded in 1969. (Anita Loring, Secretary General, International Cerebral Palsy Society, to Diane Driedger, Mar. 1, 1985 in author's possession). The International League Societies for Persons With Mental Handicap (ILSMH) was formed in 1960 by representatives of small national parents' groups. (ILSMH, What is the International League of Societies for Persons With Mental Handicap [ILSMH]? [Brussels: ILSMH, 1984], in author's possession). The International Ostomy Association was formed in 1975. (Edwin J. Ward, "A Mes-

zations Interested in the Handicapped (CWOIH), an umbrella organization of many of these international uni-disability concerned groups, was established. It was founded as a mechanism that member organizations could work through in cooperation to make presentations to the United Nations concerning rehabilitation.⁸

D. DISABLED PEOPLE

ORGANIZE INTERNATIONALLY

Four international organizations, the World Federation of the Deaf (WFD), the International Federation of the Blind (later the World Blind Union), People First International, and the Fédération Internationale des Mutilés, des Invalides du Travail et des Invalides Civils (FIMITIC) were organizations controlled by persons with disabilities. They were determined to speak for themselves and to further the aims of disability prevention.

The World Federation of the Deaf was founded in 1951. Its aims were to prevent and treat deafness, to promote the growth of national organizations of the deaf around the world, and to raise awareness about deafness.⁹ It also had consultative status with the UN and other related agen-

sage From Edwin J. Ward: The International Ostomy History, "International Ostomy Association Bulletin, Spring, 1980). The World Federation of Hemophilia (WFH) was founded in 1963. (WFH, "Information Sheet," Sept., 1984, p. 1, in author's possession). The World Council for the Welfare of the Blind (WCWB) was founded in 1951. It was formed for providing services for blind people in seventy-seven countries. The World Federation for Mental Health was founded in 1948 in London. ("What is WFMH?," pamphlet, undated). As of 1982 the World Rehabilitation Association for the Psycho-Socially Disabled was in formation. (International Psychiatric Rehabilitation Newsletter 2 [May-June, 1982]).

⁸ Council of World Organizations Interested in the Handicapped, CWOIH Compendium, 1981, (New York: Rehabilitation International, 1981), pp. 1-III.

⁹ World Federation of the Deaf, "The World Federation of the Deaf in the

cies, the World Health Organization, the International Labor Organization and UNESCO.

FIMITIC was founded in 1953. Its purpose was to bring together disabled people on common issues. Its membership was mainly from Europe.¹⁰

The International Federation of the Blind (IFB) was important to the development of DPI. It provided some future leaders. The IFB had consultative status with the UN, and it was composed of persons with visual impairments. The IFB was born out of the World Council for the Welfare of the Blind (WCWB). The WCWB was founded in 1954 and was composed of both organizations of and for blind people. But, the organizations and institutions for the visually handicapped predominated both in number and strength. One presenter jokingly remarked at a conference: "'The organizations for the blind possess the resources and the emerging organizations of the blind the ideals.'"¹¹

Differences over ideals, however, were no joke, as blind persons decided to separate from the WCWB and form their own federation consisting only of organizations made up of the blind themselves. This split took place in New York in July 1964 at the World Assembly of the WCWB. Blind people had been organizing into their own self-help groups between 1960 and 1964, mostly in Asia and the United States. In fact, the National Federation of the Blind (NFB), formed in 1960 in the US, was interested in enabling blind people in other countries to organize their own groups.

Eighties," (Pamphlet), ca. 1984, in author's possession.

¹⁰ CWOIH, CWOIH Compendium, pp. 45-46.

¹¹ Arne Husveg, "World Blind Union Founded--A Victory for Solidarity and Good Sense," Vox Nostra 2 (Feb., 1984):18.

Dr. Isabella Grant of the NFB travelled to Asia and Africa to interest blind people in forming their own organizations.¹² Representatives of seven of these organizations (from Pakistan, India, Malaysia, Hong Kong, Sri Lanka, Guatemala and the United States), attended the WCWB World Congress.¹³ There they presented a resolution asking for at least 50% of WCWB national delegations to be people who were themselves blind.¹⁴ The majority of WCWB delegates defeated this resolution. Indeed, the delegates from organizations for blind persons did not understand the need for blind people to be equally represented in an organization that dealt with their concerns.

This defeat served as a catalyst for the organizations of the blind to form their own coalition. They met outside the regular WCWB Congress sessions in New York and formed the International Federation of the Blind. They drafted a constitution that stated only organizations of the blind could have voting power. It was to be an organization controlled by the blind. By 1974, the organization had members in forty-five countries in Europe, Asia, Africa and a few in Latin America.¹⁵

The WCWB and the IFB grew along side each other for twenty years. The IFB had financial difficulties in holding World Congresses and in funding its operations. Both of the organizations received international recognition such as consultative status with the UN. In August 1984, the two or-

¹² Interview with Dr. Fatima Shah, DPI World Council Member, Kingston, Jamaica, Sept. 28, 1984.

¹³ Ibid.

¹⁴ Ibid.

¹⁵ Ibid.

ganizations decided to come together into one "World Blind Union" as a unified voice of and for blind people. An agreement was worked out, whereby the representation of blind people would be 51% in the decision-making bodies and national assemblies of the Union.¹⁶

On the other hand, mentally handicapped people began organizing internationally in 1973. In that year in British Columbia, Canada, mentally handicapped people and some social workers met at a convention sponsored by the British Columbia Association for Retarded Citizens. As a result, a group called "People First" was organized in Portland, Oregon, in 1974.¹⁷ The organization gained members in forty-one US states, and it became a national organization. Mentally handicapped people formed the organization to speak out for their rights. They asked to live in the community like everyone else, not in institutions. They had "helpers," often staff persons in institutions, who aided in the organizing of the groups. Throughout the late 1970's People First organizations were started in Canada and Sweden, thus ultimately forming People First International.

¹⁶ Interview with Bengt Lindqvist, DPI Honorary Secretary, Nassau, Bahamas, Sept. 21, 1985; John Colligan, "WCWB," in The New Beacon (Mar., 1985):83; World Blind Union, "Brief Presentation," Mar., 1985, in author's possession.

¹⁷ Jean Parker Edwards, We Are People First: Our handicaps are secondary (Portland, Oregon: EDNICK, 1982), p. 16.

E. NATIONAL AND REGIONAL ORGANIZATIONS OF DISABLED PEOPLE: PRE-1980

1. THE DEVELOPING WORLD: AFRICA, ASIA, THE MIDDLE EAST, LATIN AMERICA AND THE CARIBBEAN

Organizations of disabled people started all over the world, in local and national chapters, throughout the late 1960's and 1970's. The developing regions of the world emerging as nations from colonialism, and having poor economies, were not exempt. In fact, decolonization in Africa, in particular, spurred the development of disabled persons' organizations. The situation of disabled people in Africa, Asia, the Middle East, the Caribbean and Latin America will be discussed. Several organizations from each region, that would be instrumental in the founding of DPI through their leaders, will be highlighted.

a. AFRICA

There were more than fifty million disabled people in Africa in 1985.¹⁸ One of the leading causes of disability was malnutrition. Sixty per cent of African citizens were considered undernourished. As a result, deficiencies in vitamin A led to blindness. Diseases such as polio and river blindness were common. Even though polio virtually had been wiped out in the industrialized countries through the Salk vaccine, most people in Africa did not have access to immunization. This was partially due to lack of government health resources to make vaccines available. The greatest number of disabled people were mobility-impaired, as a result of polio.

¹⁸ Serigne Bamba N'Diaye, "Evaluation du Programme de Developpement Seminaires Africains de Dakar et Nouakchott," 1985, p. 6, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

The next most numerous group were people who were visually-impaired.¹⁹

Generally, disabled people have been the most destitute Africans. The main targets of disabling conditions were the poorest of Africans who lived in rural areas and the shantytowns of the big cities. Government planners have tended to emphasize the needs of the majority. They have ignored the needs of disabled people and their families. Disabled people generally would not work in a mainstream job. There was high unemployment among able-bodied people in Africa already. Most disabled people supported themselves by begging in the big cities, or charitable institutions supported them.²⁰

There have been few services or structures to prevent disability or to rehabilitate disabled people. The few existing services have been centered in big cities, and thus they have benefitted a very small percentage of the disabled population. The majority of African people live in rural areas.

African society's attitudes toward disabled people tended to be contradictory. Society attempted to integrate everyone into its workings and assigned each person a role, even disabled persons. But, society also held some beliefs and myths that linked disability to sins committed by disabled persons themselves or by the parents. Families saw disability as something to be ashamed of. This shame could bring about the killing of disabled children or the exile of their parents.

¹⁹ Ibid., p. 5.

²⁰ Ibid., pp. 5-6.

In addition, disabled women were in a situation of double jeopardy. African society did not accord women the same status as men. They were of lower status. Thus, disabled women faced discrimination because they were women, and because they were disabled.²¹

With the dawn of the 1980's, disabled people started to form self-help groups to work for changes in society. Wars of liberation from oppressive governments and colonialism from the 1940's through the 1970's set the stage for disabled people's struggle for freedom and independence. After all, the rhetoric of freedom was already in everyone's vocabulary as nations freed themselves from British, French, Portuguese and Italian rule. Many people became disabled as a result of liberation wars as well.

Disabled people's self-help organizations slowly became involved in solving the barriers to their participation in society. They were involved in employment training and rehabilitation programs. Organizations of disabled people arose in almost all African countries. These were both uni-disability, most often blind people's groups, and also national multi-disability groups. In most African countries organizations were founded in the cities, and there were difficulties in forming branches in the rural areas. The majority of disabled people lived in rural areas.²² Organizations of disabled people received little or no funding from their governments. They relied on non-governmental development aid agencies from the West.²³

²¹ Ibid., p. 7.

²² Ibid., p. 16.

²³ Ibid., pp. 16-17.

Mauritania and Zimbabwe had organizations that benefitted from development agency funding. Furthermore, a West African regional coalition was forged with the help of Goodwill Industries of America. Disabled leaders from these organizations would help in the formation of DPI.

First, organizations of people of all disabilities sprang up in several West African countries in the middle and late 1970's. The National Union of Physically and Mentally Handicapped Persons of Mauritania (L'Union Nationale des Handicapés Physiques et Mentaux de Mauritanie [UNHPM]) was founded in 1976. It was organized on the principle that uniting all disabled people was its strength. The founders believed, furthermore, that disabled people must take risks, that is, dare to succeed. The organization started out small and organized only in Nouakchott, the major city. It would then grow to have members in all areas of the country.

The organization embarked on employment training projects for disabled persons. In 1978, a work project was set up where ten disabled women were employed making carpets.²⁴ A year later, a center for training in sewing, embroidery and stenography and typing was started employing disabled people. Organizations such as Oxfam, Caritas in Mauritania, and the Canadian and US embassies helped in providing equipment. The aim was to provide disabled people with the skills to be integrated into the regular workforce.

The Union also took the lead in forming a regional network of disabled people's organizations in West Africa, the West African Federation for the Advancement of Handicapped Persons (WAFAH). Goodwill Industries of Ameri-

²⁴ Tambo Camara, DPI Vice Chairperson for Africa, to Diane Driedger, April 28, 1985, p. 3, in author's possession.

ca, through its international department, facilitated the formation of the network. Goodwill was an organization concerned with employment options for disabled people. In 1978, Goodwill decided to cosponsor a conference in the field of rehabilitation of disabled people in Africa. At the Conference, delegates decided they wished to form a permanent network to share ideas on disability. The organization ultimately became a disabled people's federation.

Tambo Camara (of the Union) and Susan Roche (an employee of Goodwill Industries) helped disabled leaders to find each other. In November of 1980 disabled people's groups from nine countries-- Senegal, Mali, Mauritania, Togo, Niger, Upper Volta, Benin, Guinea-Conakry and Ivory Coast met. They formed the West African Federation for the Advancement of the Handicapped (WAFAH, la Fédération Ouest Africaine des Associations Pour la Promotion des Personnes Handicapées). The organization "was conceived of as a membership organization that would bring together both rehabilitation 'professionals' and disabled persons organizations."²⁵ The distinction was blurred. Many African professionals were disabled themselves. And many disabled people's organizations, such as the Mauritanian Union, provided services, or would provide rehabilitation and employment services in the future. The intent of WAFAH was to include (not exclude) able-bodied professionals. The constitution however, did not provide for majority control by disabled people. Tambo Camara would travel to Winnipeg, Canada, in 1980 as a representative of the WAFAH, and he would participate in the founding of DPI.

²⁵ Robert Ransom, Director, International Department, Goodwill Industries of America, to Diane Driedger, July 31, 1985, p. 2, in author's possession.

Joshua Malinga also travelled to the Winnipeg World Congress of Rehabilitation International in 1980. He was one of the founders of the self-help organization in Zimbabwe. The National Council of Disabled Persons of Zimbabwe (NCDPZ) had its roots in the Jairos Jiri Association for the Rehabilitation of the Disabled and Blind. It was the biggest rehabilitation center for blacks in what was then Rhodesia. It trained disabled people in basket weaving, leather craft and shoe repairing, and offered some literacy classes.

In the mid-1960's, a disabled people's council was started within the institution.²⁶ It evolved by 1970 into the Kubatsirana Welfare Society, which meant "helping one another."²⁷ The executives of the Jairos Jiri institution were threatened by the new united voice of disabled people, who were speaking out on issues in the center. Disabled people felt they needed to speak out: "First and foremost disabled persons felt it necessary that they should represent and speak for themselves in all matters that affected them. It was out of natural necessity that such an organization be formed because disabled people were being misunderstood, ignored, misrepresented and exploited."²⁸

²⁶ Interview with Joshua Malinga, DPI Honorary Treasurer, Kingston, Jamaica, September 30, 1984.

²⁷ National Council of Disabled Persons in Zimbabwe, "The Organization of all Disabled Zimbabweans," (Pamphlet), ca. 1984, in author's possession.

²⁸ National Council of Disabled Persons of Zimbabwe, "A Voice of Our Own," Bulawayo, April, 1983, p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

In fact, it took four years for the National Council for the Welfare of the Disabled, as the self-help group renamed itself, to be registered as an organization because the service providers opposed the idea. Jairos Jiri and other agencies called these disabled people radical and ungrateful after all they had done for them. The government thought the new Council was duplicating the work of service-providing organizations. But this opposition served to spur the members of the Council on in their determination to have their own organization controlled by disabled persons. The Council was registered in 1975. But it struck a low profile until 1980 because of the big fight that had ensued over registration.

The Council entered the international arena when Oxfam funded Malinga's participation to the founding meeting of DPI in Winnipeg. Malinga knew that the philosophy he talked about with others from around the world was what was needed for Zimbabwe.²⁹

b. ASIA/PACIFIC REGION

In the 1980's, 250 million disabled people lived in the Asia/Pacific region, which included the Middle East, the Far East, South-east Asia and South Asia. The population included some of the world's poorest people. Ninety per cent of disabled people were unable to read or write. Eighty per cent of disabled persons lived in rural areas. But 90% of service and rehabilitation facilities were in the cities.³⁰ According to the World Health Organization, only 2% of disabled people received any kind of ser-

²⁹ Malinga Interview.

³⁰ DPI Asia/Pacific, "Leadership Training Seminar Asia/Pacific Re Council Disabled Peoples' International," p. 3, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

vices.³¹ According to UNICEF, 61% of the children in the entire world lived in the underdeveloped countries in this region. These children were facing a big problem, malnutrition.³²

Also, the birth of a disabled child for a family was an unhappy event:

For millions of families in absolute poverty, the birth of a disabled child (or an illness or accident producing serious impairment) places them in a slightly worse position than their neighbors. It may affect adversely the marriage opportunities of the rest of the family.³³

Many religions, such as Shinto and Buddhism, viewed disabled people as a curse on the family. They were seen as badges of shame which indicated the family may have committed some sin in the past.³⁴ As a result, people with disabilities were often hidden away.

Disabled women in particular had few options or status in the developing world:

Women in general have power as wives and mothers within the home and their status in society comes from this role. A disabled woman, in general, cannot share in this status. She is not seen as marriageable -- no one wants to arrange a marriage with 'damaged goods'. Also, in the developing world, women perform most of the labor in the home and on the fields. A disabled woman often cannot perform this work as efficiently as a nondisabled woman. Consequently a disabled woman has no status because she cannot accomplish those tasks which bring women status in her

³¹ Economic and Social Commission for Asia and the Pacific (ESCAP), "Economic and Social Commission for Asia and the Pacific Regional Program on Disability Concerns," no date, p. 2, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

³² DPI Asia/Pacific, "Leadership," p. 2.

³³ Mike Miles, "Why Asia Rejects Western Disability Advice," Quad Wrangle 6 (Dec., 1983):27.

³⁴ Aki Ninomiya, DPI Japan, "Disabled People in Japan," Address, Winnipeg, Canada, August 17, 1984, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

society.³⁵

Both disabled women and men had few options for employment and meaningful work in these societies. Many disabled people begged in the streets of the big cities, as they did in Africa. Religions called on followers to give charity to the needy, sick and disabled. People built credit toward an afterlife:

Dropping coins into the blind beggar's bowl may lead to avoidance of punishment in the afterlife.... The disabled beggar asks for 'justice'. Since fate, Karma, or deity has deprived him, begging becomes his rightful duty and occupation: justice demands that his bowl be filled. If the unseen forces present a poor family with a deformed baby, it is the family's duty to exploit the deformity for financial gain.³⁶

There were more developed countries in the Asia/Pacific region, such as Japan, Australia, and Singapore, that did not have an abundance of beggars in the streets.

Few countries had self-help organizations covering all disabilities before 1980. Many Asian countries such as Singapore, Sri Lanka, and Pakistan had blind organizations. These became associated with the International Federation of the Blind.³⁷ In Thailand, there was an organization of deaf people. In Fiji, there was an organization of paraplegics. In developed countries like Japan, there were many local and small groups of disabled people, but they were not unified nationally. In Australia, there were local self-help groups that emerged in the 1970's, but they were not very strong and were uni-disability (e.g., mentally handicapped

³⁵ Diane Driedger and April D'Aubin, "Disabled Women: International Profiles," Caliper XLI (Mar., 1986):16.

³⁶ Miles, "Why Asia Rejects." p. 27.

³⁷ Driedger and D'Aubin, "Disabled Women," p. 16.

people's groups and wheelchair users' organizations).³⁸

c. THE MIDDLE EAST

In the Middle East, there were organizations of disabled people, of one kind or another, in most countries. There was an umbrella group of people with various disabilities in Israel. In other countries, though, blind persons' organizations were the most common. In Bahrain there was a strong Mobility International organization, a travel and recreation organization, composed mainly of disabled people. Two of its members, Alice Ma'Louf and Hanan Kamal, attended the 1980 World Congress in Winnipeg.³⁹

d. LATIN AMERICAN REGION

In the 1980's, there were some thirty-four million people with various disabilities--physical, mental and emotional--in Latin America (approximately 10% of the population). Most of these persons were the poorest of the poor.⁴⁰ In Costa Rica, Cuba, and El Salvador organizations of disabled people were formed in the late 1970's. They were formed for the purpose of mutual support and to undertake action to correct injustices.

³⁸ Frank Stevens, "The Self-Help Movement," in Into the Streets: A book by and for disabled people, ed., Disability Resources Centre (Collingwood, Australia: Disability Resources Centre, 1981), pp. 11-18.

³⁹ "Roof Association of Organizations of Persons with Disabilities," ca. 1981, Disabled Peoples' International Development Office Files, Winnipeg, Canada; Dr. Y. Qaryouti, "Middle East Training Program for Leadership of Disabled Persons, First Draft," 1984, Disabled Peoples' International Development Office Files, Winnipeg, Canada; Alice John Ma'louf and Hanan Kamal, "Message," in Disabled Peoples' International 1st World Congress Souvenir Program, p. 13, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

⁴⁰ Joao Ferreira, DPI Regional Vice Chairperson, Latin America, "Regional Report of Latin America for the World Council," 1982, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

Other organizations of disabled people were based on Christianity and were formed in nine Latin American countries, such as Brazil and Honduras. These organizations, Christian Fraternities of disabled people, originated in 1942 in France. They were started by Monsignor Henri Francois. The ideas spread to countries in Europe, and Central and South America. The aim of these organizations was to promote the abilities and integration of disabled people. These groups included people with all kinds of disabilities. Disabled people held the majority on the boards of these groups.⁴¹ In Brazil, for instance, the movement started in 1942. As of the mid-1980's there were 200 nuclei, or small groups, in different regions of the country.⁴²

By the late 1970's, there were secular organizations formed in Argentina and Nicaragua as well. Nicaragua founded its organization after Somoza was overthrown in 1979. It started with young disabled war veterans.⁴³ In Argentina, the Corporación Argentina de Discapacitados (CADIS) began after the polio epidemic of 1956. Persons disabled as a result of the epidemic formed a social/recreational club. The organization was not initially involved in lobbying for changes in society. The United Nations' sponsored International Year of Disabled Persons, 1981, heightened the world's awareness about the barriers facing disabled people and the need for their integration into society. At this time, the Argentine social club became

⁴¹ Fraternidade Cristã de Doentes e Deficientes (FCD), "Fraternidade Cristã de Doentes e Deficientes (FCD)," (Pamphlet), Brazil, 1981, in author's possession.

⁴² Celso Zoppi, Fraternidade Cristã de Doentes e Deficientes (FCD), Brazil, to Diane Driedger, April 28, 1986, p. 1, in author's possession.

⁴³ Interview with Freddy Trejos Jarquin, Secretary of Organization of Disabled Revolutionaries (ORD), Winnipeg, Canada, Nov. 25, 1985.

an organization concerned with rights. Jacqueline de las Carreras, one of their main leaders, attended the founding meeting of DPI in 1980 and met disabled people there who espoused this new philosophy. She brought it back to Argentina.

e. THE CARIBBEAN

Disabled persons' groups rose against the background of decolonization, and the struggle of countries for independence in the Caribbean. Already in the 1930's, '40's and '50's people were asking for social reforms. The university campuses (especially in Jamaica) were quite radical in the 1960's. They saw that blacks declared themselves "beautiful" in the US and were waging a civil rights struggle. They saw what the US was doing in Vietnam. They viewed this as imperialism and wondered if they could be next. Indeed, the US influence in the region since the 1960's has been great--culturally, economically, and militarily with the presence of US ships and submarines. Against this background young disabled university students, particularly visually-impaired persons, led the way for disabled people's rights. They established organizations controlled by blind people in the mid-1970's.⁴⁴

It was only in the late 1970's that disabled people of all disabilities began to come together. Jamaica, seen as a leader in the Caribbean, became the first country to establish an organization of all disabled persons.⁴⁵ The Combined Disabilities Association Ltd. (CDA) was formally born in 1981. It had a great impact in Jamaica and won greater physical acces-

⁴⁴ Interview with Derrick Palmer, DPI Regional Development Officer for the Caribbean, Winnipeg, Canada, April 22, 1986.

⁴⁵ Ibid.

sibility to public buildings, gains in public education, and pioneered employment projects run by and for people with disabilities. In Jamaica, as in other developing countries, disabled people occupied the lowest rung. Some 100 social welfare organizations looked after the needs of the "less fortunate," including disabled people.

Traditionally, they have been conservative and patronizing. As a result, many social welfare projects have been known to perpetuate dependency, more so in the lesser developed ex-colonial societies where programs have been so designed that they inadvertently limit the potential of the recipients to strive towards self-reliance. This is particularly so among the disabled.⁴⁶

Thus, around 1976-77, disabled people began to get together and discuss their common concerns. In June 1981, sixty disabled people adopted the constitution of the Combined Disabilities Association (CDA).⁴⁷

The CDA asserted that disabled people themselves knew which programs met their needs. It was to be a voice of disabled people, but it would also be open to service provision, "Except where a service is lacking or requires urgent development, the CDA's policy is not to duplicate private or government agencies but to urge and assist them to extend their services to all disabled persons in society."⁴⁸

⁴⁶ Combined Disabilities Association, "Activity III," ca. 1983, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

⁴⁷ Combined Disabilities Association, "Development Program 1982-85," May, 1982, pp. 1-2, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

⁴⁸ Ibid., p. 3.

2. THE DEVELOPED NATIONS

a. EUROPEAN REGION

Blind and deaf people organized in Europe by the late 1800's in countries such as Sweden and Norway.⁴⁹ In Denmark, people with disabilities were organized into uni-disability groups in the early 1900's. These groups joined together in 1934.⁵⁰ Many organizations of disabled people began after World War II to meet the rehabilitation, technical aids and pension needs of persons disabled by the war, polio and workplace accidents. In countries such as Italy people of various disabilities organized the Associazione Nazionale Mutilati ed Invalidi Civili. Its aim was to promote the integration of disabled people.⁵¹ In post-war Netherlands disabled people formed uni-disability groups. By 1977 they united into one organization, Council of the Dutch Disabled.⁵² In the United Kingdom disabled people organized into local uni-disability groups in the mid-1970's. Service and welfare organizations for disabled persons were very strong financially and in the public's eye in Britain. People were knighted for their participation in charitable organizations for disabled people. But by November 1981 the British Council of Organizations of Disabled People was formed.⁵³ In West Germany there were two main groups, the disabled war

⁴⁹ Rolf Utberg to Diane Driedger, ca. Jan., 1987, in author's possession.

⁵⁰ H. Kallehauge, Danish Anti-Polio Society, to Diane Driedger, ca. Oct., 1986, in author's possession.

⁵¹ Associazione Nazionale Mutilati ed Invalidi Civili, "Information Sheet," no date, in author's possession.

⁵² Council of the Dutch Disabled, "Council of the Dutch Disabled," Amsterdam, Sept., 1980, in author's possession.

⁵³ British Council of Organizations of Disabled People, "British Council of Organizations of Disabled People," (Pamphlet), London, ca. 1986, in

veterans and a civilian group.⁵⁴ They were not activist oriented in their approach to issues--there was little protesting in the streets. They have received many income security and vocational rehabilitation benefits since World War II.⁵⁵

In France, the Paralysés de France was founded in 1933. It operated services for disabled people in rehabilitation, technical aids, employment and counselling. It also pressed for disabled people's rights by lobbying government.⁵⁶ In the Soviet Union there was a blind organization and a group of deaf people. There were some organizations of physically disabled people as well.⁵⁷ In Hungary local uni-disability organizations were started in 1977. By 1981, mobility-impaired people had formed a national federation of local disabled people's groups.⁵⁸

There was a regional coalition of disabled people's organizations, Fédération International des Mutilés, des Invalides du Travail et des Invalides Civils (FIMITIC) founded in 1953. Most of the European disabled peo-

author's possession.

⁵⁴ Interview with Henry Enns, DPI Chairperson, Winnipeg, Canada, July 4, 1985.

⁵⁵ Hans-Ulrich Greffrath, "The VDK of Germany Facts and Figures," ca 1986; Interview with Jim Derksen, Former DPI Chief Development Officer, June 15, 1986; Bundesverbandes für Spastisch Gelähmte und Andere Körperbehinderte e.V., Das Band (May, 1979).

⁵⁶ Association des Paralysés de France, Faire Face, (Aug., 1983); Jean Courbeyre, 1933-1983, Le Parcours de l'Association de Paralysés de France: Cinquante Ans de Créations au Service des Personnes Handicapés. Paris: Association des Paralysés de France, 1983).

⁵⁷ "Disabled in the USSR--'a Miserable Existence'," Handicaps Monthly 136 (Feb., 1982), p. 47.

⁵⁸ National Federation of Associations of Disabled Persons, "Disabled People in Hungary," Budapest, Hungary, ca. 1987, p. 1.

ple's groups belonged to this organization. Furthermore, there were many large organizations for disabled people that looked after their physical rehabilitation needs. In addition, "in many European countries there [were] non-governmental bodies for the cooperation and coordination of work between organizations in the disability field. These bodies (mainly in the form of committees or councils) [were] in most cases dominated by service providers and professionals."⁵⁹ There was one exception to this, "in the Nordic area where the organizations of disabled people in the five Nordic countries had a body of their own for cooperation and held strong positions in their national development."⁶⁰

The Swedes, through Bengt Lindqvist, a visually-impaired man, were to play a major role in the founding of DPI. Indeed, the Swedes had some of the oldest organizations of disabled people in the world. Disabled people in Sweden were organized in the late nineteenth century. The movement for the participation of disabled people in society began in the second half of the nineteenth century. At that time in Sweden popular citizens' movements (the folkrorelser), trade unionists, the temperance movement and non-conformist or "free church" movements were prevalent.⁶¹ These movements had broad grassroots support. The disabled people's movement grew

⁵⁹ Bengt Lindqvist, "Report on the development in the European region 1981-85," 1985, p. 1. Disabled Peoples' International Development Office Files, Winnipeg, Canada.

⁶⁰ Ibid.

⁶¹ Bengt Lindqvist, DPI Honorary Secretary, Interview, Kingston, Jamaica, Sept. 26, 1984; Barbro and Folke Carlsson, Social Welfare and Handicap Policy in Sweden (Stockholm: The Swedish Institute, ca. 1981), p. 26; Linnea Gardstrom, "Handicap Councils: A Swedish Experiment," in Participation of People with Disabilities: An International Perspective, eds. Kathleen S. Miller, Linda M. Chadderdon and Barbara Duncan (East Lansing, Michigan: University Center for International Rehabilitation, Michigan State University, 1981), p. 62.

amidst this atmosphere of change. They learned many lessons from observing other popular movements.

The first association formed, the Stockholm Association for the Deaf, was founded in 1868.⁶² The National Association of the Blind was founded in 1889. Throughout the 1920's and '30's, organizations of various disability groups were built, mainly those with mobility handicaps. In 1964 the Handicappförbundens centralkommitté (HCK) was born. It was a coalition of uni-disability organizations. The HCK promoted integration and rights for disabled people.⁶³

The HCK also became concerned with how disabled people defined themselves in relation to society. The group decided that disabled people were not to blame for their lack of participation in society. The medical model put forward by professionals held that disabled people could not participate because they were in the sick role perpetually trying to get better. The HCK contended that the problem of participation did not lie with disabled people and their inability to perform certain physical or mental tasks. The problem lay with society that excluded disabled persons because it assumed they could not participate. They were sick after all. Thus, society had built physical barriers, stairs and curbs. And it had erected attitudinal barriers that held that people with disabilities were sick and incapable of participation. The HCK's redefinition of disabled people's situation followed Mauss' concept of a social movement redefining

⁶² Linnéa Gardeström, "The Swedish Handicap Movement," Current Sweden 7 (Nov., 1978):1.

⁶³ The National Council for the Disabled, Associations and Societies of Disabled in Sweden Directory (Stockholm: The National Council for the Disabled, 1984), p. 34.

the problem. This redefinition process would be integrally involved in the new Disabled Peoples' International.

The HCK has been funded by the Swedish Government. To qualify for a government subsidy, a disabled people's organization must have a majority (51%) of disabled people and their relatives in its governing bodies. The Swedish government also consulted with the HCK on issues of concern to disabled persons:

The movement of disabled has to a large degree been accepted by society's bodies as a consultative partner with regard to the design of measures in the disability sphere. The disabled are given an opportunity to voice their opinion on draft bills, they take part in reference groups, working parties, committees etc., appointed to carry out special investigations at central government, country and municipal levels. They are also in many cases members of permanent bodies, e.g. boards of institutions.⁶⁴

The Swedish organizations of disabled people have had one of the longest histories in the world. They also have had the support of their government and society in changes to enable their participation in society. They also had influence in the Swedish delegation to the Winnipeg World Congress, where DPI would be initiated. Bengt Lindqvist of the HCK was to be one of the leading players in the new organization.

b. NORTH AMERICAN REGION

In the late 1960's and early 1970's, in the United States, university students with severe disabilities began the "independent living movement." In Berkeley, students at the University of California organized the Center for Independent Living (CIL) in 1972.⁶⁵ They organized the Center because

⁶⁴ The Swedish Institute, Support for the Disabled in Sweden (Stockholm: The Swedish Institute, 1981), p. 1.

⁶⁵ Hale Zukas, "CIL History," Berkeley, USA, 1976, pp. 3-4, in author's

the services they needed to live independently in the community, such as attendant care,⁶⁶ were not provided after they graduated from university. They banded together with other interested disabled people in the community, most of whom were wheelchair users. Some blind persons also joined. The Center provided attendant care services, peer counselling and a reading service for blind persons.⁶⁷

The CIL was managed and controlled by persons with disabilities themselves. Up until this point, services for disabled people were provided and controlled by able-bodied, professional service givers in institutions, hospitals and rehabilitation centers. The "independent living center" philosophy claimed that:

1. Those who best know the needs of disabled people and how to meet those needs are disabled people themselves.
2. The needs of the disabled can be met most effectively by comprehensive programs which provide a variety of services.
3. Disabled people should be integrated as fully as possible into their community.⁶⁸

Soon after the birth of the CIL independent living centers began springing up in other parts of the US on both coasts.⁶⁹

possession.

⁶⁶ "Attendant care" refers to the hiring of an able-bodied person to look after a disabled person's personal toileting needs--such as dressing, bathing, and transferring in and out of bed.

⁶⁷ Zukas, "CIL History," p. 3.

⁶⁸ Ibid., p. 3.

⁶⁹ Gerben DeJong, "Independent Living: From Social Movement to Analytic Paradigm," Archives of Physical Medicine and Rehabilitation 60 (Oct., 1979):437.

The organizers and users of these centers tended to come mainly from certain disability groups: muscular dystrophy, spinal cord injuries, multiple sclerosis, postpolio disablement and cerebral palsy. The independent living movement itself has focussed on older adolescents and young working adults or students in their twenties.⁷⁰ Also this movement grew in university communities where students were quite critical. They were freed from family and economic responsibilities, and thus they had more time and energy to organize for change.

Not only were independent living centers spawned in the early 1970's, but, a new "consumer" movement of disabled people also emerged in 1974, a national coalition, American Coalition of Citizens With Disabilities (ACCD) was struck, bringing together groups such as Disabled in Action of New York, and some independent living centers. Many of the organizations' members met each other during the fight to have the Rehabilitation Act passed.⁷¹ By 1979, the ACCD represented fifty-five groups and spoke for seven million people of various disabilities.⁷² It saw itself as a voice of disabled people, not a service-providing national organization.

The consumerism concept, that disabled people as consumers of services have a right to monitor the quality of those services, became even more pronounced in Canada. There disabled people organized a national organization in 1976. The Canadian disabled people's movement sprang up indepen-

⁷⁰ Ibid., pp. 435-436.

⁷¹ Terrence O'Rourke, "Coalition Building in the Handicapped Community," in Report on An Open National Employment Conference, COPOH, ed. Jim Derksen (Winnipeg, Canada: COPOH, 1979), p. 49.

⁷² Sonny Kleinfeld, The Hidden Minority: A Profile of Handicapped Americans (Boston: Little, Brown & Co., 1979), p. 35.

dently of the US movement; there was no contact between US and Canadian disabled people's groups. But it appeared that the US black civil rights movement, the activities of consumer advocate Ralph Nader, the women's movement and the independent living movement created a climate of change. And those new ideas spilled into Canada. Organizations of disabled persons, once again spearheaded by young mobility-impaired people, many of them university students and young professionals, had sprung up in all ten Canadian provinces by 1979. These organizations united into the Coalition of Provincial Organizations of the Handicapped (COPOH). This organization was the only national multi-disability organization in Canada. It purported to represent the interests of people of all disabilities. It lobbied the federal government for the protection of disabled people in the Canadian Human Rights Act, and for protection in the new Canadian Bill of Rights in the new Constitution.⁷³

COPOH did not provide any services for disabled people, such as attendant care, counselling or transportation. It was a voice requesting that the federal and provincial governments provide accessible services to disabled people, just as they would to all other citizens. Canada was a welfare state in that it provided subsidized medical care for all and mobility aids such as wheelchairs and crutches to people who could not afford them. Thus, for example, disabled people expected the government to provide for attendant care services in the community for persons who wanted them. This approach was somewhat different than in the US, where there was neither a universal health care system, nor an expectation that govern-

⁷³ Diane Driedger, "The Struggle for Legitimacy: A History of the Coalition of Provincial Organizations of the Handicapped (COPOH)," in Dialogue on Disability, Vol. 11, ed., Aileen Wight-Felske (Calgary: University of Calgary Press, 1987, forthcoming).

ment should look after all one's health and personal physical care needs.

COPOH and the HCK, its Swedish counterpart, were to play important roles as catalysts for the beginnings of DPI. They would be assisted by American disabled activists as well. They would bring together disabled people from different regions around the common goal of wanting their own voice. The beginnings of DPI were to take place at Rehabilitation International's (RI) World Congress in Winnipeg, Canada in 1980.

Chapter 11

PEOPLE OF ALL DISABILITIES SEEK INPUT INTERNATIONALLY, 1972-1980

A. REHABILITATION INTERNATIONAL (RI)

There was a background of organizing activity among disabled persons in the context of Rehabilitation International (RI) before 1980. This activity was characterized by disabled people asking for more participation in decision-making in RI. These were decisions about policies that affected the lives of disabled people around the world. Disabled people, most of them professionals, were denied an equal voice in RI throughout the 1970's. Finally, in 1980 disabled people asked for the last time. They broke with RI after being turned down again.

Rehabilitation International (RI) was an international organization made up mainly of rehabilitation professionals--doctors, physiotherapists, nurses and social workers. It was also the only international organization that addressed the needs of people with all disabilities. RI was founded in 1922 as the "International Society for Crippled Children." Ultimately it changed its mandate to include adults and changed its name.¹ But this organization tended to view disabled people as sick and childlike

¹ Rehabilitation International, "Rehabilitation International: 60 Years as a World Organization," International Rehabilitation Review (First Quarter), 1982, p. 1.

patients who needed professionals to care for them from cradle to grave.

RI held World Congresses every four years to discuss rehabilitation and social issues as they related to disabled people. Professionals from around the world attended. Even though the discussion concerned the lives of persons with disabilities, very few disabled people ever participated as speakers, delegates or observers. There were several reasons for their lack of participation. One was a lack of resources. Disabled people, even in the developed Western world, were some of the poorest people in their societies. Often they depended solely on a small disability pension or begging to support themselves. Many disabled people were unemployed. They could not afford such a trip, and they had no charitable organization or service agency to help them with the costs. These agencies did not view disabled persons as experts of any kind, so the amount of funding available was minimal. Able-bodied professionals were assumed to be the experts. Disabled people were to be cared for, and they were not able to contribute anything, at least according to most professionals' rationale.

Thus, RI had few disabled people participating in their Congresses until the 1970's. In Sydney, Australia in 1972, a few disabled people participated as observers at the Congress. At this time, the disabled people there gathered together for discussions.² They probably exchanged information about the issues of the Congress and the accessibility of the site. There were complaints about accessibility for people with disabilities at the Congress.³

² Norman Acton, Former Rehabilitation International Secretary General, to Diane Driedger, Aug. 22, 1985, p. 2, in author's possession.

At the next World Congress in Tel Aviv in 1976, more disabled people were present. There was still only a handful of disabled people amidst 800 delegates, but they made a militant stand. They met separately at the Congress and complained about the accessibility of the Congress site and their accommodations. There were also transportation problems. People with disabilities were loaded up into military vehicles and driven around. This was very demeaning. Disabled people felt that RI, an organization purporting to speak and act on behalf of disabled persons, was inconsistent. RI did not even think it important enough to have accessible facilities.⁴ The disabled people there concluded that it would not benefit disabled people in the long term to be a part of RI.⁵

From the point of view of the RI World Congress organizers the Tel Aviv Congress had been organized in a hurry due to unforeseen difficulties. Originally, it was planned for the German Democratic Republic (East Germany), and then it was transferred to Poland. Ultimately, because of political troubles in Poland, it was transferred to Tel Aviv. "Because of the shortness of time, it was necessary to improvise in many ways on both the program and the physical facilities for the Congress. One special difficulty had to do with the movement of people with mobility problems between various meeting sites, and there were other access snags."⁶

³ Ibid.

⁴ Interview with Henry Enns, DPI Chairperson, about Liam Maguire's views on the Tel Aviv World Congress, Winnipeg, Canada, Nov. 20, 1985.

⁵ Interview with Ed Roberts, Vice Chairperson for the DPI North American Region, on Liam Maguire's views on the Tel Aviv World Congress, Nassau, Bahamas, Sept. 18, 1985.

⁶ Acton to Driedger, p. 3.

The disabled people present, however, felt that their needs had been ignored, not only in Israel, but at previous World Congresses. They wanted physical access to RI Congresses. After all, if they could not enter the meeting site, how could they participate? At the closing plenary session of the Congress, Liam Maguire, a wheelchair user from Ireland, spoke passionately about the accessibility problems. As another participant recalled: "[He let] the participants present and the world know that merely talking about disabled people and their problems was not good enough. We needed action, accessibility and equality. We were also human beings."⁷ Furthermore, as a Swedish delegate related: "It was a plenary session and he complained very much about the bad accessibility which he thought showed that the disabled themselves were not welcomed at the meeting...I remember his speech mostly as a very impressive protest against the arrangements..."⁸

For the first time, many people within RI became aware of the frustration of disabled people. Disabled persons had the expectation that they should be treated as equals to service providers at international meetings that addressed the needs of disabled people. They had the physical mobility, education, and experience of being disabled. They believed they should be included in the planning process and thus, the meetings needed to be physically accessible to them. Disabled people experienced relative deprivation; that is, they wanted the same physical access to housing, transportation and the meeting facilities as nondisabled professionals.

⁷ Ron Chandran-Dudley, "Tribute to Liam Maguire," Disabled Peoples' International Anniversary Journal, ed. Ron Chandran-Dudley (Singapore: By the Author, 1984), p. 55.

⁸ Linnéa Gardeström, Sweden, to Diane Driedger, August 27, 1985, p. 1, in author's possession.

Disabled people wanted RI to consider their participation as important as the professionals' participation. Thus, people with disabilities staged a protest because of their perceived deprivation. And the multi-disability movement entered Mauss' incipency stage at this point. In this stage dissent on an issue is unfocussed. It takes "the form primarily of a concerned public...."⁹ People begin to hold informal ad hoc meetings in this stage and to read and postulate about issues. The response of society is "likely to be indulgent with a 'mix' containing very little repression and a lot of cooptation....Rather than generate conflict, most of the institutions and agencies of the society will attempt a restoration of the consensus through conciliation, compromise and absorption."¹⁰ The response of institutions and agencies in society causes the social movement members to define their concerns and look at how their views are different than society's definitions.

B. RI RESOLUTIONS FOR DISABLED PEOPLE'S PARTICIPATION

Ultimately, the Tel Aviv protest demonstrated the frustration of disabled people at their lack of participation in Rehabilitation International. RI decided at its Delegate Assembly (or board) meeting in Baguio, Philippines in January 1978 to begin looking at the issue of disabled people's participation in RI. There an Ad Hoc Committee on Participation of Disabled People was struck.

⁹ Armand L. Mauss, Social Problems as Social Movements (Philadelphia: J.B. Lippincott Company, 1975), p. 61.

¹⁰ Ibid., p. 62.

Throughout 1978 and 1979, the Ad Hoc Committee discussed the possibility of a draft resolution, to be presented at the next Delegate Assembly of RI, in Winnipeg, Canada in June 1980. The Draft Resolution recognized that "...in many countries increased organizational activity by persons with disabilities is taking place and is influencing the planning and provision of rehabilitation services...."¹¹

Furthermore, it affirmed it should be the policy of Rehabilitation International to:

- a. Require and assist the full participation in Rehabilitation International of organizations of disabled people.
- b. Provide that, after 1984, a requirement for membership in Rehabilitation International shall be that each member organization has adopted a policy of requiring and assisting the full participation in its governance of organizations of disabled people.
- c. Urge present member organizations to adopt as soon as possible and no later than 1988 the policy stated in the previous paragraph.
- d. Continue to actively encourage the participation of persons with disabilities at all levels in Rehabilitation International's governing bodies.¹²

While RI was addressing the participation problem, members of the RI Delegate Assembly in Sweden were discussing the same matter. In most countries, the several organizations that provided services for disabled people belonged to RI. In Sweden, however, the HCK, a coalition of various organizations of disabled persons, not just able-bodied professionals, belonged to RI. In Sweden, the HCK had input into choosing the delegation to RI's decision-making Delegate Assembly. Ultimately, the Swedish delegation was composed of four representatives of which at least two were people with disabilities themselves. Thus, this delegation very much rep-

¹¹ Rehabilitation International, "Participation of Disabled Persons in Rehabilitation International Draft Resolution, Agenda Item 10a, June 20-21, 1980," Winnipeg, Canada, in author's possession.

¹² Ibid.

resented the concerns of organizations of disabled people.

The Swedish delegation drafted a proposal for equal representation of disabled people's organizations on national delegations to the Assembly.¹³ Under this proposal disabled people's organizations would have an equal say in decision-making. The Swedish disabled people expected that disabled persons should have the same decision-making power over economic resources and social policies in RI as nondisabled professionals. Their proposal for equal representation arose out of their belief that compared to nondisabled professionals, disabled people had little say about policies dealing directly with disabled persons.

C. THE THREAT OF CANADIAN NON-COOPERATION

COPOH, the Coalition of Provincial Organizations of the Handicapped, the national organization of disabled people in Canada, also planned a strategy for disabled people's participation in Rehabilitation International at the upcoming World Congress. COPOH wanted to drive home the principle that disabled people were partners in planning services. COPOH was experiencing relative deprivation in this area. It wanted the public and professionals to recognize it had a right to an equal say in decisions about disabled people's lives. COPOH made a bid for RI membership. For this, the Canadian Rehabilitation Council for the Disabled (CRCDD), already an RI member, would have to give consent. CRCDD was an organization of rehabilitation professionals. The negotiation process between COPOH and CRCDD about membership was fraught with conflict and tension.

¹³ Interview with Bengt Lindqvist, Honorary Secretary, DPI, (1981-85), Sweden, in Kingston, Jamaica, Sept. 26, 1984.

Ultimately, CRCDC supported COPOH's membership. This signalled a victory for COPOH as a partner in planning with professionals about disabled people's lives. The Canadian government, through its Rehabilitation Bureau, helped mediate the discussions. The Canadian Government was contributing funding towards the hosting of the World Congress in Winnipeg, and it was concerned that everything go well. It had heard of disabled people's protests at the previous World Congress in Tel Aviv. The Government did not want an international incident at this event, which the media would be covering. It did not want COPOH to be protesting outside the doors of the Congress, as COPOH threatened to do if CRCDC did not accept its membership. COPOH also wished to participate in the Congress in some way.¹⁴

Ultimately, two of COPOH's leaders, Chairperson Allan Simpson and National Coordinator Jim Derksen, both wheelchair users, were asked to prepare papers on the disabled people's movement for the Congress. COPOH agreed to help with transportation and accommodation for disabled delegates to the Congress. COPOH also received a grant from the Health and Welfare Department of the Canadian Government to fund participation by fifty disabled delegates from Canada.¹⁵

¹⁴ Interview with Allan Simpson, Former National Chairperson, Coalition of Provincial Organizations of the Handicapped (COPOH), Winnipeg, Canada, February 18, 1984.

¹⁵ Telephone interview with André LeBlanc, Former Director, Bureau on Rehabilitation, Health and Welfare Canada, Ottawa, Canada, May 7, 1985.

D. A WORLD ORGANIZATION STRUCK IN WINNIPEG

COPOH geared up for the Congress in Winnipeg by arranging for its fifty delegates to arrive early, before the formal opening of the Congress. It had at its disposal several important resources which it mobilized for action: monitoring, strategies and tactics, and media coverage. It worked out a strategy on how to have input into the RI Congress, which would be attended predominantly by able-bodied professionals. The approach was three-fold.

First, it would make contact with the media and alert them to COPOH's intention to monitor the attitudes reflected in Congress papers and sessions. Second, COPOH delegates would monitor each day's activities and record them on a form that COPOH had drawn up for this purpose. The monitoring sheets would be submitted by COPOH delegates at the end of the day, and COPOH staff would then put together a daily newsheet. Third, COPOH would facilitate and organize information-sharing sessions among disabled delegates from around the world. To do all this COPOH needed an on-site secretariat. Luckily, an agency called "Concepts" had its office in the building where the Congress was to take place. This was an employment training program run for and by disabled people. Concepts offered COPOH space at the front of its office during the Congress for a secretariat.

The fifty COPOH delegates arrived in Winnipeg three days before the actual Congress and met for strategy training sessions. The COPOH "Parameters of Rehabilitation Open National Forum," held a few months earlier in Vancouver, helped COPOH members to develop policies for input into the RI World Congress. COPOH believed that rehabilitation stopped after a person

reached his/her maximum physical capacity, and that independent living for the person began after this point. Disabled persons did not wish to remain the "sick patients" of medical experts and the "caseloads" of social workers forever. Media coverage began during the planning sessions. The Canadian Broadcasting Corporation's (CBC) "Summerscope" television program began filming COPOH before the Congress and followed the disabled delegates around all week.¹⁶

RI held its Delegate Assembly meeting on Friday and Saturday, June 20 - 22, just prior to the Congress's beginning. The Ad Hoc Committee on the Participation of Disabled People and Their Organizations presented its draft resolution. Then Bengt Linqvist, a visually-impaired member of the Swedish delegation, introduced the Swedish draft resolution. It was submitted as an amendment to the RI draft resolution. The amendment called for a definition of organizations of disabled people and that such organizations should have at least 50% of the delegates in any national delegation. In other words, half of the Delegate Assembly should be composed of disabled people.

The amendment was defeated sixty-one to thirty-seven.¹⁷ This defeat was a result of feelings on the part of RI delegates that a rigid quota for disabled people's involvement should not be imposed. In their view, election to positions should be based on people's qualifications. Furthermore, some RI delegates felt that RI should reflect all interests,

¹⁶ Interview with Jim Derksen, Former National Coordinator, COPOH, Winnipeg, Canada, Feb. 18, 1984.

¹⁷ Lindqvist Interview; Rehabilitation International, "Report of the Meeting of the Assembly, Winnipeg, Manitoba, Canada, June 20-21, 1980," pp. 6-7, in author's possession.

professional, government and disabled people's organizations in its organization. Within that framework, they could give increased attention to disabled people's participation in the future.¹⁸

The Swedish delegation was angered by the amendment's defeat. It believed that the RI draft resolution, which was passed without the Swedish amendment, was just words. It had no power to force RI members to include disabled people in decision-making. Disabled persons wanted to have equal input with professionals immediately, not in the future. Indeed, many disabled people, themselves professionals in social work and other rehabilitation disciplines, attended this Congress for the first time in significant numbers. They were proving that disabled people could indeed work and contribute to society like all so-called normal people. They were no longer in need of rehabilitation. They wanted to speak for themselves about how services could better be delivered to maximize their independence in the community. Their rising expectations had been frustrated by RI.

About 250 persons with various disabilities attended the Congress. Many of them were American professionals who were disabled. Some of these and those from other countries had been invited to participate in the program of the Congress, such as Derksen and Simpson of COPOH. Another example was Ed Roberts, one of the founders of the independent living movement in California, and the Director of Rehabilitation for the State of California.¹⁹ RI invited these people to increase the participation of people

¹⁸ Acton to Driedger, p. 3.

¹⁹ Roberts Interview; Acton to Driedger, p. 4; "A Summary of Proceedings, ACCD, RIUSA, Rehabilitation International Exploratory Meeting," Washington D.C., May 1, 1978, p. 2, Coalition of Provincial Organiza-

with disabilities.

Other disabled people, especially from North America, had the money to pay their own way because they had professional jobs. In addition, COPOH had fifty of its own delegates funded by the Canadian Government. Furthermore, because the United Nations International Year of Disabled Persons, 1981, was fast approaching, some persons with disabilities (particularly from developing countries) received funding from non-governmental organizations to attend.²⁰ Most of these disabled people represented organizations of disabled persons in their countries. COPOH facilitated communication among the disabled people attending the Congress.

The daily COPOH Newsline, evaluating the events of the Congress, was disseminated to the thirty hotels where Congress delegates were housed. A taxi cab driver had been recruited to deliver these. The Newsline was placed on the desks of reporters in the media room every morning as well, thus ensuring media coverage of the disabled people's struggle to be heard. The local RI Congress organizers became aware that this Newsline was becoming very popular and causing commotion. Some of the organizers went to the media room and collected all the copies of the Newsline from the desks before the reporters came in one morning. One of the reporters caught them and told them to leave the Newsline alone, because "that was the only interesting thing happening at this Congress."²¹ The Newsline

tions of the Handicapped (COPOH) Files, Winnipeg, Canada.

²⁰ Interview with André LeBlanc, former Director Bureau on Rehabilitation, Dept. of Health and Welfare, Canada, Ottawa, Canada, June 10, 1985; Interview with Joshua Malinga, DPI Honorary Treasurer, Kingston, Jamaica, Sept. 30, 1984.

²¹ Derksen Interview, Feb. 18, 1984.

also furthered communication among international disabled delegates and COPOH. It announced separate information-sharing meetings that COPOH hosted outside of Congress hours.

COPOH sponsored an Interfaith Seminar and Church Service, for international delegates to share experiences, on the Sunday preceding the Congress, June 22, 1980. This event was well attended and international disabled delegates displayed an interest in sharing with Canadian disabled people. COPOH decided to host an information-sharing meeting on Monday night, the first night of the Congress. The Swedes, angered about their resolution's defeat, swept into the June 23 information-sharing meeting called by COPOH. There 250 disabled people from forty countries learned from Bengt Lindqvist that RI had defeated the equality resolution. An immediate bond was created among the disabled people. The group decided that there was a need for an autonomous organization of disabled persons:

A tremendous roar filled the Convention Centre in Winnipeg, Canada that Monday evening June 23, 1980. The question was repeated, 'Do I hear you say you want a World Coalition of Citizens With Disabilities?' The unanimous response came back, echoing to every corner of the World Congress of Rehabilitation--'Yes!'. The some three hundred [sic] delegates who gathered there from all parts of the globe had a sense of their own destiny. They wanted to proclaim their rights, as citizens, to an equal voice in the decision-making of services, the policies and programs that affected them. They were no longer willing to passively accept the control of rehabilitation professionals over their lives. They demanded dignity, equality and full participation in society. They demanded release from the yoke of paternalism and charity...²²

²² Henry Enns and Allan Simpson, "Decade of Destiny of and for Handicapped People," 1980, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

An Ad Hoc Planning Committee was struck to discuss the philosophy, organization and structure of such a world organization.²³ Representatives of Canada, Costa Rica, India, Japan, Sweden and Zimbabwe made up the Committee. It met several times over the next few days.

The Committee presented its findings at the next meeting of disabled delegates on June 25. The group accepted its proposal for a structure and philosophy for starting up an international organization. A Steering Committee was struck with two representatives from seven regions of the world.²⁴ Henry Enns of Canada was elected Chairperson and Bengt Lindqvist of Sweden was chosen as Vice Chairperson. The organization was struck in great excitement as a declaration of independence from the control of rehabilitation professionals.

The new organization's name was the World Coalition of Persons With Disabilities (WCPD). It would be renamed Disabled Peoples' International (DPI) in the coming months. The organization would be composed entirely of persons with disabilities. Its philosophy was equality and justice: "The World Coalition of Persons With Disabilities should be based on the philosophy of equal opportunity and full participation of handicapped people in all aspects of society as a matter of justice rather than charity."²⁵ The organization was to be multi-disability, that is, organiza-

²³ ibid.

²⁴ World Coalition of Persons with Disabilities, "Minutes of Meeting by Steering Committee 1980-06-26, Winnipeg, Canada," p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

²⁵ Kathleen S. Miller, "Disabled People Coming Together Internationally," in Participation of People with Disabilities: An International Perspective, eds. Kathleen Miller, Linda M. Chadderdon, Barbara Duncan (Michigan: University Centre for International Rehabilitation, Michigan State University, 1981), p. 149.

tions of persons of all disabilities would be members. Furthermore the organization's philosophy was one of "self-representation": "The coalition should be firmly committed to the principle that handicapped people are their own best spokespersons. Therefore, the organization should be made up of organizations 'OF' the handicapped rather than 'FOR' the handicapped."²⁶

The Steering Committee was mandated to draft a constitution for the new organization, to plan a first world congress to found the organization, and to build organizations of disabled people around the world.²⁷ Finally, the gathering recognized RI's contribution to the new world voice: "We compliment Rehabilitation International for making possible the vehicle for the formulation of the world coalition."²⁸

There were different reactions to the formation of this breakaway group at the RI Congress. One group was incredulous. They were mainly nondisabled professionals. They believed that disabled people would not be able to form their own world organization.²⁹ These professionals tended to patronize disabled people. This was perhaps one of the reasons the equal participation resolution was defeated. They believed disabled people were not ready to speak out for themselves. Ed Roberts, the quadriplegic Director of the Department of Rehabilitation in California, claimed that

²⁶ Ibid., pp. 149-50.

²⁷ Ibid., p. 151.

²⁸ "Report of Ad Hoc Committee for World Coalition of the Disabled," June 25, 1980, p. 2, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

²⁹ Roberts Interview.

several of these people even had patted him on the head.³⁰

The patronizing attitude of professionals reflected their view that disabled people were patients to be cured. This was the traditional medical model view. As Linnéa Gardeström, a member of the Swedish delegation observed: "Doctors and others working for disabled persons as patients just could not understand why disabled people were now unsatisfied. They looked upon disabled people as weak and in need of assistance from the experts. The rehabilitation professionals had always done their best, why were not disabled people grateful?"³¹ But, disabled persons were redefining their situation in the world, as other social movements redefine the problem in Mauss' theory. They asserted that they were not helpless, passive patients. Rather, they were citizens with rights. Disabled people wanted to represent themselves as Jim Derksen, COPOH National Coordinator, told the media: "Rehabilitation International is a service organization concerned with services not rights. They don't have the direct experience (of being disabled)."³²

Some rehabilitation professionals present agreed that disabled people should form their own organization to represent themselves. Rehabilitation International had arranged for more disabled people to participate in the Winnipeg Congress than ever before. They had been granted places on the program. RI anticipated and welcomed the possibility that disabled

³⁰ Ibid.

³¹ Linnéa Gardeström, Member of the Swedish RI Delegation to Winnipeg, Canada, 1980, to Diane Driedger, April 4, 1985," p. 1, in author's possession.

³² Laurie Streich, "International coalition created by handicapped," Winnipeg Free Press, June 26, 1980.

people would get together. Some rehabilitation people though, believed disabled people were going through a phase, but this was a more positive than negative thing. Archie Carmichael of the Society for Crippled Children and Adults of Manitoba, summed up this view:

Most of these people have gone through our 'process' and many have been very successful vocationally and/or socially. After all, the purpose of rehabilitation programs is to attain maximum independence. Consumer groups can do many things other programs cannot do. These groups and organizations are new and have not as yet had the benefits of long experience. To me, they are going through a developmental stage which resembles the adolescent or young adult in a family, who often becomes rebellious for a period of time. After this stage, an excellent partnership and relationship with the 'family' evolves and life goes on better than ever.³³

This was not the view of the disabled people who left Winnipeg and started organizing the new world organization. Indeed, they would be patronized no longer. They were not children as some professionals viewed them--they were adults who were taking control of their lives and destiny as they should. They declared the power over their own lives that they believed should have been given to them.

Instead, disabled persons had to wrest power from those with the money and technical resources who would not grant them control. These resources in most countries were controlled either by government or by charitable fund-raising events such as telethons. This form of fund-raising capitalized on the stereotypes the public held about disabled people as pitiful and helpless. The public was moved to contribute money out of guilt and also out of fear that they might catch a disabling condition. Thus,

³³ J.A. Carmichael, Executive Director, Society for Crippled Children and Adults of Manitoba, to Rev. Harold H. Wilke, July 21, 1980," p. 1, Society for Manitobans with Disabilities (formerly Society for Crippled Children and Adults of Manitoba) Files, Winnipeg, Canada.

these conditions needed to be cured before that happened. Most often, cute "crippled" poster children were used to elicit pity. This reinforced the stereotype that disabled persons were perpetual children who needed to be cared for and given handouts. Indeed, the World Coalition Steering Committee began its struggle to raise money to organize. Without resources, disabled people could not get together internationally or hold a world congress of their own to launch Disabled Peoples' International (DPI).

The disabled Congress participants had, though, used many resources successfully to mobilize the new international multi-disability movement. The Canadians and Swedes emerged as leaders to successfully build on the frustration felt by the disabled delegates. Both the Canadian and Swedish disabled people employed strategies and tactics with great success to drive home the need for disabled people to be equal partners in decision-making. The Swedes came to the RI Assembly meeting with a draft resolution calling for equal participation. When it was defeated the Swedes recognized the chance to share their frustration with other disabled people at COPOH's information-sharing meetings. COPOH, on the other hand, came to the Congress well-prepared to state their case that disabled persons should have an equal say about their own lives. COPOH planned its mobilization tactics well before the Congress took place. First it insisted that it be given membership in RI and be recognized as an equal partner with the CRCDD, the Canadian professionals' organization. Second, it obtained government funding to bring fifty disabled people to Winnipeg to monitor the Congress for how it viewed disabled persons in the planning process. It also planned a forum for the results of this monitoring

through the media, such as the Summerscope program. COPOH was so successful in using the media to advance the cause of disabled people, that the reporters defended the disabled participants' right to have their Newsline read by reporters. The media lent credibility to the demands of disabled people at the Congress. After all, the media viewed their break-away from RI as valid news.

Furthermore, the disabled participants formulated a philosophy and a slogan for the movement that reflected its beliefs: "A Voice of Our Own." Disabled people would represent themselves and call for their own full participation in society.

Thus, the multi-disability international movement completed Mauss' incipency stage and moved on to the coalescence stage. First, in the incipency stage disabled persons defined their concerns in the disabled people's meetings; they wanted equal decision-making in RI. They experienced frustrated rising expectations. They perceived themselves as adults who should be involved in the planning of policies that affected disabled people. Indeed, many of the disabled participants were also professionals who saw themselves as having as much expertise and education as their non-disabled counterparts. Furthermore, their own experience with disability made them the experts on what disabled people wanted. Thus, they perceived that RI was denying them their right to decide on issues affecting them. They had been denied this right after the Swedes' resolution for equal participation was defeated. As a result of experiencing this relative deprivation, the disabled people present decided to form an ad hoc body to create their own organization. The professionals' response to this was mixed, but some did express hostility in the form of paternalism.

This is a symptom of the incipency stage: "This boundary testing [of defining the problems in different ways from society] will begin to arouse some hostility in the society, for it will involve some rejection of the compromise and cooptation offered by society."³⁴ Indeed, disabled people rejected RI's resolution for the participation of disabled people, which did not immediately guarantee them an equal decision-making role.

The Steering Committee that was formed quickly ushered DPI into Mauss' "coalescence stage." This stage develops, "in response to repressive and provocative acts on the parts of the government or of other institutions of the 'establishment.'"³⁵ In this stage ad hoc committees are formed and formal organizations are embarked upon. The World Coalition of Persons with Disabilities Steering Committee was a response to RI's refusal to grant disabled people an equal say in decision-making in RI. They aimed to create a formal mechanism to confront their oppression. Disabled people would make their own decisions in their own organization.

³⁴ Armand L. Mauss, Social Problems as Social Movements (Philadelphia: J.B. Lippincott Company, 1975), p. 62.

³⁵ Ibid.

Chapter III

THE STEERING COMMITTEE LAYS THE FOUNDATION FOR A WORLD ORGANIZATION, 1980-81

A. STEERING COMMITTEE MEETINGS

The Steering Committee to establish DPI consisted of eleven members after the World Congress. Three positions remained open--one from Latin America, one from Asia, one from Oceania. Two of the positions were filled over the next half year. The Steering Committee met three times throughout 1980 and 1981 to prepare a constitution, draft a statement of philosophy, and to organize a founding world congress for the World Coalition. These Steering Committee members were of varied backgrounds and disabilities. A few had had experience in international organizations through RI and the International Federation of the Blind. Others had years of experience with national organizations of disabled people. Most of the members were professionals in various fields. Their ages ranged from thirty-five to forty-seven years of age.

At this stage of organization, the leadership was mainly of a charismatic nature. According to social movement theorist Mauss, when a movement for change coalesces, or comes together, charismatic leaders take center stage. They motivate their followers. Often they also set out the philosophical underpinnings of the movement:

To what extent charisma comes from a leader's own personality traits, and to what extent it is projected by a membership or by a certain crisis situation is not clear. But he who has it is followed because the membership believes he has truth and justice on his side and that he has the right to lead them.¹

There is no structure at this point. Leaders are needed that can be trusted and who will set a direction for the membership.

The Steering Committee members of DPI were elected because they were seen by the other disabled people at the RI Congress to represent their interests and to have "truth and justice" on their side. Furthermore, the leadership was from what would be called the middle classes of society. This is typical of most social movements. Also, the leadership tended to be from the free professions as in other social movements. Leadership in such movements tends "to be lawyers, teachers, writers and other intellectuals, who are freer, both socially and temporally to conceive and advocate new ideas and policies."²

Henry Enns, a representative of North America, and Chairperson of the Steering Committee, played an instrumental role in raising funds for the Founding Congress of DPI. Enns, a wheelchair user, had been involved with self-help organizations in Canada at the provincial and national levels since 1975. He was a social worker by training. In 1980 he had just started working as a consultant on disability issues with the Mennonite Central Committee (MCC) for Canada, which had its head office in Winnipeg. Through the Mennonite Central Committee, Enns gained the first contacts for funding the Steering Committee meetings of the World Coalition. John

¹ Armand L. Mauss, Social Problems as Social Movements (Philadelphia: J.B. Lippincott Company, 1975), p. 62.

² Ibid., p. 53.

Wieler, Overseas Director at MCC, encouraged Enns to contact the Canadian International Development Agency (CIDA) and referred him to MCC's CIDA contact, John Mackrae.³ Support from MCC, an organization well-known to CIDA as a reliable non-governmental development and relief agency, helped the World Coalition to obtain a CIDA grant of \$17,200 (Cdn.). It was granted for the World Coalition to hold the first Steering Committee meeting in Ireland in 1980.⁴ The money was granted to COPOH because the World Coalition was not yet incorporated. COPOH would administer the money for the Coalition.

Several important decisions were made in Dublin. Ron Chandran-Dudley a visually-impaired Singaporean, offered Singapore as the site for the founding world congress and the Steering Committee accepted his offer. It was felt that Singapore was a good place for the congress because it bridged the developed and developing worlds.⁵ It was industrialized, yet it was still a developing world nation. The World Congress would be held in December 1981, that is, at the end of the United Nations International Year of Disabled Persons.

The Steering Committee also decided to accept the constitution written by Liam Maguire. It would be presented to the first world congress in

³ Interview with Henry Enns, DPI Chairperson, Winnipeg, Canada, Nov. 5, 1985.

⁴ Romeo Maione, Director General, NGO Division, Canadian International Development Agency, to J. Derksen, Executive Director, COPOH, Oct. 30, 1980, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

⁵ Henry Enns, "Report of Steering Committee," Winnipeg, November, 1981, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

Singapore.⁶ The constitution was modelled on that of the International Labor Organization. Maguire was deeply involved with labor concerns and with the ILO. DPI's structure would comprise seven regions, with regional councils for each region, and a "world council" with five representatives from each of the regions. Furthermore, Maguire's constitution suggested a name change for the organization: Disabled Peoples' International (DPI). The change from World Coalition for Persons with Disabilities was proposed because to the Europeans "coalition" meant a short term agreement between political parties to permit a government to function. It did not signal a lasting relationship. According to Enns, "It was felt the word coalition had a negative connotation being associated with short term make-do arrangements characterized by instability."⁷

The mood before the Steering Committee meeting was uncertain and exploratory. The attitude was that it would not really be possible to start an organization. There was little enthusiasm and considerable skepticism on the part of some of the members before the Ireland meeting. Yet, the Irish meeting was a turning point. DPI actually received funding from CIDA and Aer Lingus for airfares, and the Mayor of Dublin hosted the Steering Committee. These events all lent legitimacy to the group. Everyone left the meeting feeling that they would give this organization their best effort to get it going.⁸

⁶ Disabled Peoples' International, "Meeting of the Steering Committee Oct. 18 and 19, 1980, Dublin, Ireland," p. 3, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

⁷ Enns, "Report of the Steering Committee," p. 3.

⁸ Enns Interview, August 29, 1985.

The next Steering Committee meeting was held in San Francisco, February 15-17, 1981. This meeting was funded by the United Nations Trust Fund. This had been set up for the International Year of Disabled Persons (IYDP) in 1981. UN member governments contributed to the Fund. DPI ultimately received support as a result of contacts that Henry Enns, the DPI Chairperson, made while attending UN meetings in the summer of 1980. (This meeting will be discussed later in this chapter.) The UN granted \$21,000 (US) to bring the Steering Committee members to California. The Department of Rehabilitation in California also contributed \$5,000 (US).⁹

At the California meeting, the program for the World Congress was approved. A program committee was set up with Maguire as Chairperson. The program would focus on how to organize disabled persons' organizations, issues of disabled people and development and peace, and DPI's relationship to other international organizations (such as the UN and the ILO).

Tempers flared over language issues. Tambo Camara, a French-speaking African from Mauritania, expressed his displeasure that documents sent to him were not translated from English into French. The working language of the Steering Committee was English. All the other Steering Committee members spoke English. He had raised this issue in Dublin, but he felt the translation situation had not improved since that time. Other Steering Committee members were tired of hearing his complaints. Furthermore, at this point the Steering Committee members began asking what they were going to get out of this organization, and how would it benefit their organizations?

⁹ Disabled Peoples' International, "List of Donations and Grants to DPI (Canada) Inc., 1980-85," Winnipeg, 1985, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

Finally, people began to realize that they wanted a world organization, and to organize it they had to work together.¹⁰ It was agreed that French, English and Spanish translation would be provided when needed.¹¹

There were no such conflicts at the next meeting in Toronto, July 31 and August 1, 1981. By that time, Jim Derksen had agreed to be a part-time acting international coordinator out of Winnipeg, Canada. The Menno-nite Central Committee had seconded a voluntary service worker, Diane Driedger, to act as administrative assistant in the office. The Toronto meeting was held with leftover UN funds. It was held in conjunction with a Mobility International (MI) conference. Mobility International was an international travel organization that brought disabled people together to meet each other, to socialize, and to discuss barriers to disabled people's participation. MI paid the airfare and hosting costs of several DPI Steering Committee members who spoke at MI's conference. Some of the Steering Committee members could not be present. In fact, there was no official quorum. The meeting was held though, because it was the last chance to plan for the upcoming World Congress in December 1981.

Several decisions were made at the meeting. It was felt that the seven geographical regions in the constitution should be changed to the five the United Nations used. And the World Council would have five members from each region.¹²

¹⁰ Enns Interview, August 29, 1985.

¹¹ Disabled Peoples' International, "Minutes of Steering Committee of Disabled Peoples' International in San Francisco, USA," Feb. 15-17, 1981, p. 2, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

¹² DPI, "Steering Committee Minutes--York University, Toronto, Canada, July 31 and August 1, 1981," p. 5, Disabled Peoples' International De-

A subsidy program to bring developing world delegates to Singapore was also discussed. The first priority was to fund the actual on-site expenses of the Congress. Secondly, DPI would attempt to fund one delegate from each country in the developing world. While it was difficult for all disabled people to obtain funding to attend a congress, it was especially hard for developing world people to find resources because their governments and economies were also poor.

The morale at the meeting was quite upbeat. Ron Chandran-Dudley and a volunteer organizing committee in Singapore were busy making logistical arrangements. Some funds had been promised by CIDA, the World Council of Churches and the UN International Year of Disabled Persons Trust Fund, though DPI had not received them yet. Everyone thought 200 people would be a good turnout. At the time of the Toronto meeting, DPI had heard from thirty-six countries about their interest in attending DPI's founding congress.¹³

B. PROMOTING DPI REGIONALLY

The Steering Committee members publicized the Congress to disabled people around the world and helped groups of disabled people organize. Joao Ferreira organized a Latin American Symposium on Rehabilitation in Costa Rica as part of his role as consultant to the Costa Rican government. He travelled extensively in Central and South America publicizing this event and DPI's upcoming Congress. Many disabled people attended the Latin American Symposium. Henry Enns, Chair of the Steering Committee, spoke about DPI

velopment Office Files, Winnipeg, Canada.

¹³ Diane Driedger and Jim Derksen, "Correspondance Report," July, 1981, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

at the Symposium. These people organized an "American Association of Handicapped People," a coalition of people from countries such as Argentina, Nicaragua, Venezuela and Costa Rica.¹⁴ Jacqueline de las Carreras organized a multi-disability organization in Buenos Aires, Argentina during 1981 called, Corporación Argentina de Discapacitados (CADIS).¹⁵

In the Asian region, the Japanese organized a loose coalition of existing organizations of disabled people called the "Japan Committee for the Development of DPI."¹⁶ They raised funds through a benefit concert. As a result, the Japanese appeared 105 delegates strong in Singapore.¹⁷ Senator Eita Yashiro also raised \$60,000 (US) for the production of a Congress film.¹⁸

In Australia, Gustav Gebels had difficulty interesting people to attend the World Congress at first. He initially approached the government-sponsored International Year of Disabled Persons group which was not a self-help group. Ultimately, though, local self-help groups of disabled people

¹⁴ Enns, "Report of Steering Committee," p. 9; DPI, "Latin American Addresses," 1981, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

¹⁵ Interview with Jacqueline de las Carreras, DPI World Council Member, Kingston, Jamaica, Sept. 28, 1984.

¹⁶ Diane Driedger, "From Winnipeg to Singapore," in A Voice of Our Own: Proceedings of the 1st World Congress of Disabled Peoples' International Nov. 30-Dec. 4, 1981, Singapore, eds. Kathleen S. Miller and Linda M. Chadderdon (Michigan: University Centre for International Rehabilitation, Michigan State University, 1982), p. 5.

¹⁷ Disabled Peoples' International, "1st World Congress 1981 Participants List," 1981, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

¹⁸ Disabled Peoples' International, "List of Donations and Grants to DPI (Canada) Inc., 1980-85," Disabled Peoples' International Development Office Files, Winnipeg, Canada.

became interested in attending the Congress.

The Australian Government granted \$10,000 (Australian) for twenty disabled people to attend the Singapore Congress. They joined another twenty-five interested Australians who raised their own money. Forty-five Australians would attend the Congress.¹⁹

In Africa, both Steering Committee members were organizing their regions. Tambo Camara helped complete the formation of a regional organization of disabled persons' groups in French-speaking West Africa, the West African Federation for the Advancement of the Handicapped (WAFAH), in November 1980. This coalition included organizations in Cameroon, Burkina Faso (then Upper Volta), Mali, Mauritania, Niger, Senegal, Sierra Leone and Togo.²⁰

Joshua Malinga returned to Zimbabwe inspired by the happenings of the Winnipeg Congress. He had gained a clear understanding of the DPI philosophy of disabled people speaking for themselves and demanding their right to participate in society. He founded a self-help organization of disabled people, Council for the Welfare of Disabled Persons in Zimbabwe.²¹ Malinga also spread the word about DPI's upcoming Congress in countries such as Kenya, Zambia and Botswana.²²

¹⁹ "History of DPI," in When Others Speak for You, You Lose, Proceedings of the First National Assembly Disabled Peoples' International (Australia) Melbourne 1983, ed. Jeff Heath (Adelaide: The South Australian Chapter of Disabled Peoples' International, Inc., 1984), p. vi.

²⁰ Driedger, "From Winnipeg to Singapore," pp. 4-5.

²¹ Interview with Joshua Malinga, DPI Honorary Treasurer, Kingston, Jamaica, Sept. 30, 1984.

²² Driedger, "From Winnipeg to Singapore," p. 5.

C. PROMOTING DPI AT THE INTERNATIONAL LEVEL

Meanwhile, Henry Enns, the Steering Committee Chairperson, publicized DPI and its philosophy at the international level throughout 1980 and 1981. Most importantly, he travelled to the United Nations Advisory Committee meeting for the International Year of Disabled Persons in Vienna, August 20-29, 1980. Enns attended as a consultant to the Canadian delegation on disability issues. His presence at the meeting resulted in some international visibility and funding for the fledgling DPI.

Originally, a member of the Canadian Organizing Committee (COC) for the International Year of Disabled Persons was supposed to attend. Enns was not on the COC. A colleague of his from COPOH, Percy Wickman, a wheelchair user, and Co-Chair of the COC, was to attend the Advisory Committee meeting. At the last minute he could not attend. It looked as though other members of the Committee, who were nondisabled, were likely candidates to go in Wickman's stead. But, COPOH, through Jim Derksen, Wickman and Allan Simpson lobbied Health and Welfare to send a disabled person. They wanted to send Henry Enns. André LeBlanc, the Director of the Bureau on Rehabilitation, also agreed that Enns, a disabled person, should go. Nondisabled members of the COC felt they should go. Ultimately, with pressure mounting on both sides of the question, Enns received approval for his attendance from Health and Welfare and was off to Vienna.

Other members of the Canadian Delegation were David Smith, MP, Walter Dinsdale, MP, André LeBlanc, Bureau on Rehabilitation, and Jim Crowe, from the Canadian Embassy in Vienna. There were only a few disabled people at-

tending the meeting. The US delegation included Frank Bowe, a deaf man who had been at the founding meeting of DPI in Winnipeg. Bengt Lindqvist, Vice Chair of the Steering Committee, was a member of the Swedish delegation.

The Vienna meeting was important because the twenty-three nation Advisory Committee was in the process of drafting a World Program of Action Concerning Disabled Persons (WPA), for the International Year of Disabled Persons and its follow-up. It had already held one meeting in 1979. The WPA document was to address the definition of disability, the needs of disabled people in rehabilitation, and prevention of disabilities. Enns and Lindqvist wanted the WPA to include recognition of disabled people's right to integration and participation in society. They also wanted recognition of the importance of building disabled people's organizations.

The meeting provided a forum for Disabled Peoples' International (then called the World Coalition of Persons with Disabilities) in 1980. The Canadian delegation was supportive of disabled people's participation and organizations. They put forth a motion that Enns be granted observer status as a representative of the new DPI.²³ It was accepted at the meeting. Enns thus was able to speak on behalf of DPI and represent the concerns of disabled people around the world. The support of the Canadian delegation for the principles of disabled people's participation was invaluable. It helped the fledgling DPI gain international recognition as a representative of disabled people.²⁴

²³ Telephone interview with André LeBlanc, Former Director, Bureau on Rehabilitation, Health and Welfare Canada, Ottawa, Canada, June 10, 1985.

²⁴ Henry Enns, "International Disability Issues: Canadian Involvement," Winnipeg, March, 1985, pp. 5-6, Henry Enns, Disabled Peoples' Interna-

Enns also furthered the credibility of DPI as a world voice of disabled people outside the formal sessions. He managed to talk with many representatives of countries telling them about DPI, its plans, and philosophy. He encouraged them to support the participation of disabled people from their countries in the upcoming World Congress. Enns had credibility in talking about what disabled people wanted because he himself was disabled.

By the end of the meeting, the Advisory Committee decided that a World Conference of disabled persons was needed.²⁵ The Trust Fund for the International Year would have funding for the participation of disabled people through their organizations as one of its priorities in 1981. Thus, some contacts for funding DPI activities were made. Ultimately, funding for the California DPI Steering Committee meeting was secured through Enns' discussions with UN officials.²⁶

In August 1981, Enns was again a member of the Canadian Delegation to the Advisory Committee as a representative of DPI. Enns discussed funding for the DPI Founding World Congress with Otto Wandall-Holm, who was in charge of the IYDP Trust Fund. It looked as though funding of around \$60,000 (US) would be granted. Indeed, DPI was able to obtain money resources to further its aims. It gained legitimacy with international organizations (United Nations), development agencies (MCC), and governments (Canada). These bodies granted funds to the emerging movement to hold

tional Chairperson, Files, Winnipeg, Canada.

²⁵ UN Advisory Committee for the International Year of Disabled Persons, "VII Recommendations, B. 'World Conference OF Disabled People,' Second Session, Vienna August 20-27, 1980, Agenda Item 8," p. 2, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

²⁶ Enns Interview, August 29, 1985.

meetings and hire staff.

Chapter IV

THE DPI FOUNDING WORLD CONGRESS IN SINGAPORE, 1981

A. THE CANADIAN SECRETARIAT SEARCHES FOR FUNDS,

MAY - DECEMBER, 1981

While Steering Committee members were organizing groups and publicizing Disabled Peoples' International (DPI), Jim Derksen, Acting International Coordinator and Diane Driedger, Administrative Assistant, worked to raise funds for the World Congress budget of almost \$240,000 (Cdn.).¹ Resources to run the office came from a variety of sources. The Manitoba League of the Physically Handicapped donated some space in their Winnipeg office to DPI. The Canadian International Development Agency (CIDA) non-governmental division provided another grant of \$25,000 after the California meeting for secretariat expenses and for Derksen to be employed part-time.² Derksen had been a staff person with disabled people's organizations locally and nationally (with the Coalition of Provincial Organizations of the Handicapped) since 1975. He was a wheelchair user.

¹ "DPI World Congress Budget," 1981, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

² Henry Enns, Chairperson of DPI Steering Committee, to Peter Hoffman, Non-Governmental Division, Canadian International Development Agency, March 12, 1981, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

The Mennonite Central Committee Canada (MCC), in addition to allowing Henry Enns to work on DPI business as part of his job at MCC, recruited Diane Driedger as a voluntary service worker to work with DPI. Driedger was a nondisabled person who had worked with the Manitoba League of the Physically Handicapped in the summer of 1980.

Derksen and Driedger sent out letters to international funding bodies to raise monies for the Singapore Congress. They did this in consultation with Enns, who checked into Winnipeg every several months. Enns travelled across Canada extensively with his MCC job. None of the three had any previous experience with international organizations or funding bodies. Derksen extrapolated from his national experiences in Canada and thus steered his way through the international funding maze.

It was important to raise funds to sponsor developing world delegates to Singapore. The price of an air ticket from Africa, Latin America, and even Asia would be a person's income for a whole year. Without a subsidy program, few disabled people from the developing world would be present to accept the constitution and elect a World Council representative of all regions.

DPI had difficulties in its application for CIDA funds. DPI applied to the International Non-governmental Division (INGO) of CIDA for support. The INGO division agreed to grant \$100,000 to the Congress. But, DPI needed to be incorporated as a legal body in Canada to receive the grant. The Canadian Secretariat had filed an application for incorporation in 1981. Complications arose in the application process. Thus, the CIDA money, over one third of funds promised, was in jeopardy, as Driedger related in frustration:

Our lawyer forgot to include the name search sheet, which she had prepared, in our application for incorporation. The bureaucrats in Consumer and Corporate Affairs in Ottawa took three months to read our by-laws and then sent them back in September because of the missing name search. With the Congress and the need for funds growing ever nearer she sent the name search to Ottawa. Three weeks later we were informed that we needed a limit on our board of directors and thus, our application was rejected again! Infuriated, we envisioned one hundred thousand dollars slowly slipping through our hands.³

After this comedy of errors, an ally in Health and Welfare helped prod the acceptance of the incorporation in Ottawa, and the Letters Patent were approved and arrived in Winnipeg at the end of October. Proof of incorporation was fired off to CIDA and the Canadians waited for the money.

With less than a month until the start of the Congress, air tickets had to be purchased for developing world delegates. Some fifty disabled people were waiting at their end to hear if they would be sponsored to go to Singapore. At the beginning of November, the Canadian Secretariat had only \$20,000 from the World Council of Churches and promises of funds from the UN and CIDA.

Derksen, Enns and Driedger worked out a strategy. Some risks had to be taken to ensure the representation of twenty-five developing world countries in Singapore. They arranged a line of credit with two travel agencies, one in Winnipeg and another in Ottawa. The firms paid for the tickets and sent them to disabled people in Africa, Asia, Latin America and the Caribbean. These people needed to scramble to obtain visas, permission to leave their country, and leave of absence from jobs, all within a two week time period. By November 20, some fifty tickets had been

³ Diane Driedger, "First Voluntary Service Report from Diane Driedger to Mennonite Central Committee," Winnipeg, Nov. 14, 1981, p. 4, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

sent, and still the Canadian office only had \$20,000. Altogether, \$120,000 in air tickets had been sent. Derksen assured the travel agents that money was coming to pay for the tickets by the time the Congress started.

Thus, six days before the Congress, on November 23, the Canadians left for Singapore and took all the money they had with them. They left with travel agents waiting for payments, and tickets sent all over the world, not knowing if they had reached their destinations. And Jim Derksen often said in those last two weeks, "We're all going to jail if that money doesn't come."⁴

B. HAPPENINGS IN SINGAPORE

Meanwhile, the Singapore Organizing Committee for the Congress was making last minute hosting plans. They had received very few registration forms. They believed if 200 people showed up that would be a good turnout. They had organized the local hosting arrangements for the Congress in seven months.

The Organizing Committee was a collection of twelve disabled and nondisabled people who were mostly professionals--doctors, teachers, business people and government workers.⁵ Ron Chandran-Dudley, a member of the Steering Committee, was their link to the Canadian Secretariat. The Organizing Committee booked the Hyatt Regency Hotel as the site for the Con-

⁴ Diane Driedger, "Second Voluntary Service Report to Mennonite Central Committee, A Struggle Ends, Another Continues," Winnipeg, p. 2, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

⁵ "Singapore Organizing Committee Minutes," April 22, 1981-December, 1981, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

gress. It ensured that the Hyatt was made accessible with ramps to the front doors and into restaurants.⁶

The Steering Committee arrived several days before the Congress to discuss last minute details. While these discussions went on disabled delegates began to arrive in Singapore. The Canadians watched to see how many of the tickets they sent had reached their destinations. It ended up that all but three people made it to the Congress. The people sponsored by the subsidy program raised the countries represented from twenty-six to fifty-one.⁷ Indeed, to all the organizers' surprise 400 disabled people arrived in Singapore for the World Congress, more than anyone had ever imagined.

They came, people of all disabilities. Some were sponsored by DPI, others by governments, and still others raised money any way they could:

Many had borrowed, sold, worked, begged--anything to raise the funds to be able to attend. Such was the man from Zimbabwe who is blind and bicycled from Salisbury to Bulawayo 441 km to raise funds for his organization of the blind to send him to Singapore.⁸

Others raised enough for airfare, and arrived with the faith that somehow DPI would pay their accommodation and meals for the week. The Canadians were approached time and time again for assistance, and it was provided.

⁶ Driedger, "From Winnipeg to Singapore," p. 5.

⁷ Ibid., p. 6.

⁸ Kathleen S. Miller, "A Chorus of Voices: A Commentary," in A Voice of Our Own, Proceedings of the First World Congress of Disabled Peoples' International, Nov. 30 - Dec. 4, 1981, Singapore, eds. Kathleen S. Miller and Linda M. Chadderdon (Michigan: University Centre for International Rehabilitation, Michigan State University, 1982), p. 81.

While people were arriving, Derksen and Driedger were waiting for word from Canada that the money had arrived. They divided the money they had brought with them into meal allowances for the fifty subsidized delegates. This used the last of the money. By Thursday, December 3, one day before the Congress was to end, Derksen phoned Bill White of the Coalition of Provincial Organizations of the Handicapped (COPOH). Derksen said he was going to jail if some money was not wired to Singapore to pay the \$20,000 Canadian hotel bill by the next day. Derksen asked White to try to obtain a credit line at the bank and wire the money.

The previous Friday, White had heard from the United Nations that the money was coming. He went to COPOH's bank and showed them the UN telegram promising the money. But, the UN funds had not arrived yet. COPOH was broke, so he arranged a line of credit for \$20,000. He got Canadian External Affairs to send the money through diplomatic channels so that it would arrive faster. Indeed, it arrived the next day in Singapore, and the Canadian High Commissioner's office delivered the money to Derksen's hotel room.⁹ The money, from both CIDA and the UN, arrived in DPI's Winnipeg bank account after the Congress was over.

Meanwhile, political difficulties arose over the representation of China at the Congress. The People's Republic of China informed the Singapore Organizing Committee that it was sending five delegates to the Congress. The Congress organizers and the Steering Committee assumed that Taiwan was not attending the Congress since representatives from that country had not registered ahead of time. Thus they believed there would be no problem

⁹ Interview with Bill White, former COPOH National Coordinator (1981-1984), Winnipeg, Canada, Dec. 30, 1983.

concerning the representation of China. Then, five Taiwanese delegates arrived unannounced. The People's Republic delegates followed a day later. They found that the Taiwanese had already begun representing the "Republic of China," and their name tags indicated this. The people in charge of the registration table assumed that the Taiwanese delegates were the People's Republic delegates that were expected to attend. The People's Republic delegates refused to attend the Congress unless Taiwan added "Republic of China, Taiwan Province" to their name tags. The People's Republic representatives stayed in their hotel rooms for the whole Congress. The Steering Committee negotiated with both sides on this matter. The dispute remained unresolved. The Chinese, in a written statement, expressed their interest in working with all countries, while expressing their regret that they could not participate.¹⁰ Thus, international political troubles were very much a part of this meeting just as at any other international meeting.

Yet the Congress was a joining of common purposes. Everyone had the common experience of being disabled and wanting to participate in society. The opening day of the Congress, November 30, included UN dignitaries and speeches by disabled people on the philosophy and goals of organizations of disabled persons. Tactics for organizing national coalitions were also outlined. The first day, though, ended with some delegates questioning the legitimacy of the process of accepting the constitution.

¹⁰ Chinese Delegation, "Statement by the Chinese Delegation to the DPI World Congress," Singapore, December, 1981, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

After the opening speeches, members of the British Delegation asked to present a written statement to the Congress. They were not allowed to do so due to insufficient time, according to the Steering Committee members who chaired the session. The British felt their views were being squelched. They circulated a written statement, which expressed dissatisfaction with the little time set aside to discuss the constitution. Indeed, it seemed the Steering Committee wanted the constitution it had prepared rubber-stamped. Their organization in Britain, the British Council of Organizations of Disabled People (BCDOP), had mandated the British delegates to tackle several constitutional concerns. They had obtained a copy of the draft constitution before the Congress. They had tried to speak with Liam Maguire, author of the constitution, about these issues several days before the Congress, but Maguire did not want to discuss any changes.¹¹ He felt possessive of the document he had already created. Furthermore, the British delegates tried to bring up constitutional issues with Henry Enns and the Steering Committee. They felt they were ignored.

Thus, the written statement they circulated expressed dissatisfaction with the definition of "disability" and "handicap" in the constitution. It was the World Health Organization's medical definition.¹² They wanted a definition of handicap that explained that disabled people were handicapped by barriers in society. When these barriers, such as inaccessible buildings, were removed, disabled people would be able to participate like everyone else. They did not want disabled individuals to be blamed for

¹¹ Interview with Vic Finkelstein, British Council of Organizations of Disabled People, Nassau, Bahamas, Sept. 20, 1985.

¹² British Delegation, "Statement from the U.K. Representatives," Nov. 30, 1981, p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

their lack of participation in society. Indeed, the inaccessible environment was to blame. Again, this was an example of disabled people redefining the social problem of disability. The blame for non-participation lay with the medical model, which viewed disabled people as helpless, passive patients who spent their lives getting well.

The British delegates then began to lobby others who were also dissatisfied with the process. They wanted to push for time on the Congress agenda to discuss constitutional changes. The British delegates, Vic Finkelstein, Stephen Bradshaw and Francine White, hung posters in the foyer outside the main meeting room. They called on people to attend a meeting of "The People" that evening. The inference was that the Steering Committee members were dictators who wished to make decisions autocratically. The small room was full that night, indicating that others were at least interested in, if not supportive, of the charges against the Steering Committee. Many of the delegates at the meeting wanted time on the Congress program to discuss the proposed constitution. In the end, Henry Enns attended the meeting to announce that the Steering Committee had decided to suspend the regularly scheduled sessions the next day to discuss the constitution.

Emotions ran high on both sides of the constitutional issue. The Steering Committee felt their months of work to create a new organization might be thwarted. If the constitution was not accepted in the next four days, DPI would not be born in 1981. Other Steering Committee members felt their authority was being questioned. They thought they had done a good job, and now the Congress delegates were unfairly criticizing their efforts. The British, on the other hand, believed that DPI must be based

on democratic principles, and be directed by "The People," the grass-roots.¹³

The next day's session became a constitutional debate as people from each of five regions of the world broke up into their regional groups to consider the constitution. In addition to the definitions of disability, and handicap, there was the issue of whether parents and nondisabled advocates could be a part of DPI. There was heated discussion about this issue. Some people, from countries such as Japan, did not want parents to be involved at all. The delegates believed parents tended to overprotect their disabled children and wanted to keep them dependent. But, disabled people wanted to be adults, not protected children all their lives. By the end of the week, however, the constitution was accepted. The Congress participants decided that the new World Congress would discuss the definition and further amendments. And parents whose children were underage could be involved. Furthermore, individuals chosen by intellectually disabled persons could be involved.¹⁴ But, the national organization in each country would decide its own membership criteria. Of course, organizations had to be 51% controlled by disabled people.

The Congress accepted other official documents as well. It approved the "Charter," now changed to "Manifesto," and a "Plan of Action" for the organization. The "Manifesto" dealt with the philosophical base of the organization: "We maintain that all people are of equal value. This conviction implies that disabled people have the right to participate in

¹³ Ibid., pp. 1-2.

¹⁴ Jeff Heath, "First World Congress of Disabled Peoples' International--A Regional Report," 1982, p. 6, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

every sphere of society....We therefore reject all forms of segregation and we refuse to accept lifetime isolation in special institutions."¹⁵ It also asserted the basic rights of disabled persons as citizens of the world: the right to education, rehabilitation, employment, independent living and income security. It also stated that disabled persons should have the right to influence governments and decision-making processes: "...organizations of the disabled must be given decisive influence in regard to all measures taken on their behalf."¹⁶ DPI, thus, had its philosophy of disabled people speaking for themselves for full participation accepted by its membership. This philosophy would be one of DPI's main resources in its future mobilization.

World problems that caused disability were discussed, as the "Singapore Declaration" adopted by the Congress indicated: "Join us in our condemnation of policies that produce waste and destruction, policies of violence and war, policies of perpetuating disability...."¹⁷ Workshops were held on these problems. One workshop on disability and armaments claimed that war was the number one cause of disability.

By the end of the week, the Congress passed a resolution stating that 1% of all monies spent on the arms race should go towards preventing disability. In a plenary session, the exploitative nature of multinational corporations in developing nations was cited as a primary cause of malnutrition and disability. Liam Maguire of Ireland stated:

¹⁵ "DPI Manifesto," 1981, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

¹⁶ ibid.

¹⁷ Disabled Peoples' International "Singapore Declaration," 1981, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

Of the world's 500 million severely disabled people, at least 100 million are severely disabled solely because of malnutrition. At least one million babies per annum die because of the misuse of powdered milk infant food, which multinational companies aggressively sell to mothers in developing countries. Four million more suffer brain damage from baby-bottle malnutrition.¹⁸

Many goals were realized in Singapore. There was a feeling of liberation symbolized in the "Wheelchair Disco." Everyone danced together. It was a realization that all people express themselves in their own way. By the end of the week, not only were the Constitution, the "Manifesto" and the "Plan of Action" accepted, but a World Council was also elected. Twenty-five persons, five from each of the five regions of the world, were elected to the governing body of DPI for four years. The World Council elected Ron Chandran-Dudley, of Singapore, the Chairperson, and Henry Enns as Deputy Chairperson. Bengt Lindqvist, of Sweden, was elected Secretary, and Joshua Malinga, from Zimbabwe, became Treasurer. As well, a vice chair was elected from each of the five regions to represent regional interests. The World Council agreed that it would meet again in the summer of 1982.

In all, the new World Council was a continuation of the charismatic leadership elected to the Steering Committee. All but one of the original members, Gustav Gebels, were re-elected to the new Council. The criticism could be made that the Steering Committee members were hanging on to power in what was supposed to be a grassroots organization. But, social movement theorist Mauss contends that charismatic leadership is needed in the

¹⁸ Liam Maguire, "How to Start Organizations of Disabled People," in A Voice of Our Own, Proceedings of the First World Congress of Disabled Peoples' International, Nov. 30-Dec. 4, 1981, Singapore, eds. Kathleen S. Miller and Linda M. Chadderdon (Michigan: University Center for International Rehabilitation, Michigan State University, 1982), p. 32.

beginning stages of social movement organization. The Steering Committee members had laid the philosophical and organizational framework for the organization. They had inspired 400 disabled people around the world to attend the founding congress. The Congress participants decided that these leaders had demonstrated their leadership in the formative stage of DPI. They re-elected these charismatic leaders to represent them.

Personal goals were met for many disabled people at the Congress. Cristina Figari, of Argentina, organized four United Nations interpreters, and one of the top government interpreters in Argentina to come as volunteers to the Congress in Singapore. She herself was the sixth interpreter in the team.¹⁹ She was a government interpreter in Argentina, and was certified to be a United Nations interpreter. Yet, the UN turned down her requests for employment because she was a quadraplegic. The UN deemed workplace modifications impossible. Figari proved in Singapore that she could interpret, and that the soundproof booths could be made wide enough and ramps could be built, so that she could gain easy access.

Other people with disabilities had never travelled outside their country before. They met people from other cultures. They discovered that concerns about disabled people's participation and equality went beyond political borders. Many new friendships and love affairs were embarked upon. Most importantly, people left filled with excitement about the potential of this world voice. They carried their enthusiasm back to their countries. Disabled people were resolved to create and build national organizations of disabled people in their countries and regions. They also would create employment and technical aids projects and lobby government

¹⁹ Miller, "A Chorus of Voices," p. 82.

and service providers for changes.

Thus, DPI was established as a formal organization representing the international multi-disability movement. The members of DPI again managed its resources successfully to mobilize their movement. They received funds from many organizations, including the United Nations. They used strategies and tactics successfully to sponsor the participation of fifty developing world disabled people in the Congress. As a result, some twenty-five countries had representatives that could not have attended without the subsidies.

The movement mobilized its leadership and membership effectively to accept its basic philosophical documents and to elect its first World Council. The leaders, though, were unable to deal successfully with the question of the representation of China at the Congress. The People's Republic delegates, who represented millions of disabled people, were unable to participate.

DPI appeared to continue in the next several years in Mauss' coalescence stage. In this stage social movements solidify their formal organization at all levels, local, regional, and in the case of DPI, international. Thus, DPI concentrated on building its infrastructure and publicizing its existence nationally and internationally.

Chapter V

DPI'S IMPACT ON LOCAL ORGANIZATIONS, 1982-85

A. INTRODUCTION

The disabled people who attended the Singapore Congress returned home inspired to continue building organizations in their regions. By 1985, there were disabled people's organizations, either uni-disability or multi-disability, in virtually every nation of the world. DPI's founding served to provide organizations with an international voice and an impetus to consolidate national multi-disability coalitions, where none existed. DPI monies also served to help disabled people organize themselves through leadership training seminars.

There were three different approaches that DPI could have pursued. First of all, monies could have been employed to build organizations of disabled people in developing areas and to build and strengthen the infrastructure of DPI. Secondly, DPI could have raised monies to provide assistance through socio-economic projects, such as employment generating schemes. Finally, DPI could have concentrated on developing more accommodating societal infrastructures. This meant lobbying against environmental and attitudinal barriers that impeded disabled people's participation in society.

DPI decided that the building of disabled people's organizations must come first in the development process. DPI's philosophy was that there needed to be organizations of disabled people to start self-help development projects. Organizations should be built so that persons with disabilities could decide collectively what kinds of projects they needed.¹ This chapter will explore the DPI Development Program and then examine the ways DPI national members dealt with socio-economic and societal barriers in different regions. DPI's impact on these activities will be discussed.

B. THE DPI DEVELOPMENT PROGRAM

1. ORIGINS OF THE PROGRAM

After the Singapore Congress, DPI sought ways to expand its membership. DPI enacted a Development Program as its main vehicle to build the organizational infrastructure of DPI. In addition, the Development Program also contributed to the building of local and national organizations of disabled people.

The main thrust of DPI's program was "Self-Help Leadership Training Seminars." The rationale was that DPI would train disabled people in the developing world to help themselves. In the developing world, many people begged for a living. While training new leaders was the purpose of the Development Program, after three years of operation it appeared that at least half of the program's participants were already advantaged disabled people. Thus, only half were people who had little or no leadership ex-

¹ Interview with Jim Derksen, Former DPI Chief Development Officer, Winnipeg, Canada, June 15, 1986.

perience. This meant that women, poor people, and certain disability groups, such as those with mental disabilities, were grossly underrepresented.²

Disabled people's groups in the developing regions have organized such seminars since 1982. By 1985, seminars had been held in Thailand, Bangladesh, Australia, Senegal, Zimbabwe, Mauritania, Barbados, and Argentina. Each of these seminars included persons from fifteen to twenty countries in the region. The DPI Development Office in Winnipeg coordinated the funding. The Canadian International Development Agency, United Nations, Catholic Development and Peace, the Mennonite Central Committee and others contributed money. Local disabled persons' organizations raised funds for on-site expenses.

The idea for a development program originated at the Ecumenical Church Service of the 1980 RI World Congress in Winnipeg. Developing world delegates related some of the difficulties they had in obtaining wheelchairs and crutches. People in the Western countries had many mobility aids, opportunities and services, and left the meeting with a feeling that they should help disabled people in the developing world.³

² From surveying existing participants lists of five of the seminars, there is indication that just over half of the participants had not been leaders in organizations before. Some of the seminars were mainly of existing leaders, such as in Zimbabwe in 1985, and in Barbados in 1983.

³ Derksen Interview, June 15, 1986.

2. THE PROGRAM

In the Spring of 1982, Derksen, Acting International Coordinator, and Enns, Deputy Chairperson, met with people in the International Non-governmental Organizations section of CIDA. Henry Enns' portfolio as Deputy Chairperson was to investigate how to ensure that disabled people in the developing world were involved in DPI. Enns and Derksen were looking for funds for this purpose. CIDA indicated that it could support projects that were oriented toward leadership training.⁴ At the same time, the Swedes reported their SIDA (Swedish International Development Authority) was interested in contributing about \$300,000 (Cdn.) to the program.

The Canadians presented a development project proposal to the World Council in Tokyo in 1982. DPI would ask CIDA for \$425,000 and SIDA for \$300,000 for an eighteen month project.⁵ The total program would cost \$1,260,000 (Cdn.).⁶ The World Council adopted a "Self-Help Leadership Training Program" which included training exchange programs, regional training seminars, regional development officers, and a small project fund.⁷

This program had to be cut back because the Swedish funding did not come through as a result of the change of government. Sweden however, did commit funds to the operations of the DPI Secretariat.

⁴ Interview with Henry Enns, DPI Chairperson, Winnipeg, Canada, Nov. 5, 1985.

⁵ Derksen Interview, June 15, 1986.

⁶ Aldredt Neufeldt, et al., An Emerging Voice, Report to Disabled Peoples' International on its Self-Help Development Program (Winnipeg: Disabled Peoples' International [Canada] Inc., 1985), p. 2.

⁷ Derksen Interview, June 15, 1986.

Nevertheless, CIDA decided to provide \$90,000 for a scaled-down eighteen-month Interim Self-Help Leadership Development Program. It started in 1983. CIDA provided one-third of the monies for the project, with the Development Office channelling one-third from other agencies, and the local organizations raising one-third. The budget was over \$176,500 for the total program.⁸ DPI held three training seminars in its first eighteen-month program funded by CIDA. In 1983-84, CIDA granted another \$250,000 for leadership training and also provided money for a small projects fund. In sum, most of the program focussed on leadership training between 1982 and 1985.

The leadership seminars were initiated to train disabled persons to lead self-help organizations in the developing regions of the world. Self-help groups enabled disabled persons to lobby their governments for improved job opportunities, transportation, education, and access to public buildings. Experienced disabled leaders and organizers from the developing world conducted the meetings. The rationale was that after a two-week seminar the newly-trained leaders could go back to their countries and organize a disabled people's organization. Or, they could use their knowledge in existing organizations to teach others new skills.

Budgetting, writing project proposals, and management were discussed, as well as leading meetings and lobbying governments and agencies for changes. The philosophy of DPI was also affirmed. Disabled people were to speak for themselves to governments and to society.⁹

⁸ Disabled Peoples' International Development Office, "Report 1983," pp. 2-3, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

⁹ Yukiko Oka, ed., The Engines are Ready, Let's Go! Report of DPI Asia/Pa-

The Seminars, held 1983-85, benefitted disabled people in many ways:

While some skills may be acquired through a one-week seminar, the opportunity to establish connections with other people facing similar circumstances in other lands is of even greater significance. Seminars of this nature usually are only as successful as the networks of communication which are created between people attending. Furthermore, by holding highly visible events of this nature, the opportunity is created to influence policy makers, professional and general public attitudes and practices.¹⁰

The seminars also strengthened DPI as an organization. They affected the growth of national organizations: "Some have reported growth in membership by as much as 75%. The number of countries having some relation to DPI have grown from 41 in 1980 to over 100 in 1985."¹¹ For example, the Guyana Coalition of Citizens with Disability was founded in October 1983, after some disabled people from Guyana participated in the 1983 Barbados seminar.¹²

The Leadership Training Seminars also made it financially possible for the regions to hold DPI regional Assembly and Council meetings. They were held in conjunction with the training seminars. This meant that delegates' airfares were subsidized under the training seminar program, and on-site expenses for the regional meetings held before or after the training seminars were raised from other sources. But this had negative effects, as Council members were funded to attend both seminars and Council

cific Leadership Training Seminar, April 20-24, 1983 (Japan: DPI Japan, 1983); Jeff Heath, ed., Developing Leaders: Report of Disabled Peoples' International Leadership Training Course, Adelaide, 1984 (Adelaide: DPI [Australia] Inc., 1985).

¹⁰ Neufeldt, et al., An Emerging Voice, pp. 2-3.

¹¹ Ibid., p. 16.

¹² Joseph Skeete, "Guyana Coalition of Citizens With Disability Report," ca. 1986, Henry Enns, DPI Chairperson, Files, Winnipeg, Canada.

meetings. Thus, funds were spent to send experienced leaders to the events, though they did serve as resource speakers in many cases. But the seminars were at least leadership training for the disabled people organizing the seminar. They were members of the local organizations of disabled people in the host country.

There were some difficulties in the planning for the seminars. The program content was too broad. Too many areas were being covered in a week-long seminar. Specific skills in accounting, fund-raising, and management were not delved into enough. The participants would have liked more intensive instruction in these areas. There was a problem, though, with the different levels of skill and experience of people who attended the seminars. This led to "unevenness in participation and at times, a disjuncture between the level and choice of content and the capacity and interests of some of the participants."¹³ This was as a result of many experienced leaders attending the seminars.

Due to the presence of experienced leaders, many people were denied the chance to participate. Most seminars had no representation from mentally handicapped people or persons with psychiatric disabilities. In most seminars, males outnumbered females by a wide margin. Most of the participants were employed. More than half of the people had mainstream jobs and were not necessarily working with disabled people (though some did). Others were self-employed.¹⁴ Thus, there was an absence of women, certain disability groups and the poorest disabled people at the seminars. Overall, though, the seminars did succeed in providing a vehicle for disabled

¹³ Neufeldt, et al., An Emerging Voice, p. 36.

¹⁴ Ibid., p. 9.

people in various regions to meet each other and share common concerns.

3. REGIONAL DEVELOPMENT OFFICERS

Regional Development Officers (RDO's) were an added feature of the Development Program in 1985. They were hired to foster the creation and strengthening of disabled people's organizations. The officers hired in 1985 were: (1) Eileen Giron for Central America based in El Salvador; (2) Derrick Palmer for the Caribbean, based in Jamaica; and (3) Miguel Amuchastegui for South America based in Argentina. The officers made contact with organizations of disabled people in their region. They also encouraged disabled people to start employment projects and to lobby their governments for changes.

The officers were successful in raising the public profile of disabled people's groups and in creating new organizations of disabled people. Derrick Palmer helped people with disabilities organize in Belize, Grenada, Trinidad and Tobago, St. Kitts and the Bahamas.¹⁵ He played the role of motivator in getting people together. No doubt, he would have used the organizing efforts of other disabled people connected to DPI as examples of how to organize and what benefits could be gained from organizing. Furthermore, the DPI Development Program Evaluation found that for self-help groups "being tied to a visibly strong international body gave both individual participants and the groups they represented more credibility, both with their members as well as with governments and the public."¹⁶ In-

¹⁵ Henry Enns and Derrick Palmer, "North American/Caribbean Regional Report," ca. 1985, Henry Enns, DPI Chairperson, Files, Winnipeg, Canada; Carlton Stevenson, Chairperson, "Grenada Council of the Disabled (GNCD)," October 31, 1986, in author's possession.

¹⁶ Neufeldt, et al., An Emerging Voice, p. 16.

deed, in the Caribbean, Palmer's visits helped disabled people's organizations to gain credibility with their governments. Often, when Palmer came to visit different Caribbean countries, meetings were arranged with the country's Prime Minister or President, as in Guyana or Trinidad. Representatives of the local disabled people's groups went along too. These officials learned that the disabled people's movement had a credible international and regional base.¹⁷ DPI, after all, had consultative status with the UN's Economic and Social Council and ties with other international bodies. Thus, governments perceived local and national disabled people's groups as having clout.

4. INTERNATIONAL SYMPOSIUM ON DEVELOPMENT, JAMAICA, 1984

DPI also sponsored an International Symposium on Development in Kingston, Jamaica, in October 1984. Its purpose was to begin discussions between representatives of disabled persons' organizations and development agencies. Some ninety people attended the meeting. Over half of these people were from disabled people's groups. Unfortunately, few of the invited development agencies were able to attend. Many appeared reluctant to spend funds attending a conference. One wonders, though, whether the agencies viewed disabled people's issues simply as unimportant. Yet, another factor contributed to the agencies' poor attendance. DPI sent out invitations for the event only four months before it was to take place. DPI should have started planning the event much sooner. The development agencies that did attend talked about disability projects they were operating. DPI shared its view that it was important to build organizations so that

¹⁷ Interview with Derrick Palmer, DPI Regional Development Officer for the Caribbean, Winnipeg, Canada, April 22, 1986.

disabled people could help themselves in the development process. There was general agreement that disabled people and development agencies should work together in planning projects for disabled persons.

5. THE EUROPEAN REGION

The DPI Development Program only attempted to develop organizations in the developing regions. The European Region was not included in this program at all through funding or leadership training. The European members were not able to raise funds for organizational development in Europe. Only eight countries were members of DPI by 1985.¹⁸ There had been no leadership training seminars once a year to invite organizations to, and to help finance DPI internal meetings in Europe. Even in Europe, disabled people were the poorest of the poor. They did not have money readily available to enable them to meet together.

Europe had a wide array of organizations of disabled people. In many cases they had existed longer than in other parts of the world. But, most of them did not join DPI. The lack of development money was only one reason why the European Region was so underrepresented in DPI. Another reason was the existence of a regional disability coalition in Europe. The Fédération Internationale des Mutilés, des Invalides du Travail et des Invalides Civils (FIMITIC) grouped seventeen organizations of disabled people across Europe. According to Simonetta Bencini, of the Italian organization, Associazione Nazionale Mutilati ed Invalidi Civil,

We never contacted DPI directly; it may do a good job, but as we joined FIMITIC in 1953 and are cooperating in its different Commissions we do not feel the need to join another organization

¹⁸ Cyprus, Denmark, Finland, Netherlands, Norway, Portugal, Sweden and United Kingdom.

with similar goals.¹⁹

FIMITIC had the same goal as DPI: disabled people themselves must speak out for their own integration and equality.²⁰ It also had consultative status with UN Economic and Social Council (ECOSOC), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the International Labor Organization (ILO), and the World Health Organization (WHO). The European organizations that belonged to FIMITIC could compare similar experiences, and use them to improve legislation in their countries. Indeed, with an organization already existing in Europe, why should organizations join DPI?

People within DPI, on the other hand, claimed that FIMITIC was not a strong organization. They were not represented at UN meetings, such as those for the drafting of the World Program of Action Concerning Disabled Persons. They claimed it was more of an organization on paper, not active, and certainly not activist.²¹ Furthermore, it was primarily composed of mobility-impaired people; they did not have other disability groups represented. Jan Johnsson, of the DPI Secretariat, further stated that FIMITIC was a dying organization, and it did not have the enthusiasm that DPI had about working for the equality of disabled persons.

¹⁹ Simonetta Bencini, Associazione Nazionale Mutilati ed Invalidi Civili, to Diane Driedger, October 9, 1986, p. 1, in author's possession.

²⁰ Fédération International des Mutilés, des Invalides du Travail et des Invalides Civils (FIMITIC), "FIMITIC," (Pamphlet), Paris, ca. 1986, in author's possession.

²¹ Telephone interview with Jan Johnsson, Head of DPI Secretariat, Stockholm, Sweden, November 18, 1986.

FIMITIC, on the other hand, claimed to represent all disabled people, and to have people of all disabilities involved in the organization. It believed that it provided a mechanism by which European organizations could share information and expertise on issues that they had in common. FIMITIC argued that disabled people in Europe had their own unique perspective. Thus, European organizations benefitted from sharing with each other. They would not necessarily benefit from sharing with disabled people in other regions. FIMITIC did not bar organizations in other regions from membership.²² It had corresponding members in other regions.

FIMITIC's head secretariat was funded through membership fees. It received no funding from other sources. The congresses that FIMITIC held every four years were funded by the national hosting organizations, which were all in Europe. There were no funds to subsidize delegates who could not afford to attend. Thus, developing world corresponding members would find it difficult to attend a congress. It would not be easy for disabled people in regions outside Europe to participate in FIMITIC.

As for attendance at UN meetings, FIMITIC was not present at the World Program of Action Concerning Disabled Persons discussions or the International Labor Organization meetings on the Vocational Rehabilitation Convention. This was due to a reorganization of FIMITIC at the time. In the final analysis it believed it had a large enough struggle to see that disabled people in Europe gained their dignity and the right to a decent standard of living. Even in Europe, disabled people were the poorest of all citizens.

²² Marija Stiglic, Secretary General, FIMITIC, to Diane Driedger, Mar. 4, 1987, in author's possession.

Overall, the prior existence of FIMITIC, coupled with the lack of money for meetings, slowed down the European Region's participation in DPI. The death of Liam Maguire of Ireland, the Vice Chairperson for Europe, in 1983, also created a vacuum. There was no one responsible for pulling together the European Region until 1985. The DPI Secretariat in Sweden made some efforts, but not in a major way. The Secretariat was already understaffed and thus organizing the European within DPI was not its first priority.

6. FUTURE DIRECTIONS, 1985-1989

In 1985, DPI conducted an evaluation of its Development Program for 1983-85. A team of seven people was chosen to interview disabled participants and also people who were with UN bodies or international aid agencies who had worked with DPI. Six of the seven team members were disabled persons, and the different regions of the developing world were each represented. The evaluation was a valuable exercise for DPI in assessing its past activities. It was undertaken, at the request of CIDA, to assess the effectiveness of the Leadership Training Seminars. The evaluation affirmed that the leadership training seminars had achieved their objectives to a large extent. Indeed, the seminar participants interviewed felt the content of the seminars generally was what they needed. Furthermore, the effect of leadership training has been felt through the founding of multi-disability self-help organizations around the world.

The evaluation report made recommendations for the future of the development program. It was affirmed that DPI should continue its development program. It should include underrepresented groups: women with disabili-

ties, those with mental and psychiatric disabilities, and the poor. Furthermore, it was affirmed that leadership training should continue. Regional Development Offices and Officers should be continued. Regional offices should be established in regions where there were none.²³

There was a problem, though, with the design of the Development Program Evaluation. One wonders whether it could truly assess the effectiveness of the program. In the evaluation only disabled people who had benefitted from the program were interviewed. Thus it was very likely that they would respond that the program was good for them. After all, it enabled them to travel and to meet new people at no cost to themselves. How the program affected, or had the potential to affect, the masses of poor disabled people in developing countries was not measured in the study. Many of the training seminar participants were from middle class backgrounds. Perhaps some poorer disabled people who did not participate in the leadership training program could have been interviewed to assess what impact they thought the DPI program had, or could potentially have, on their lives.

It was interesting that the evaluation did not question whether the organization-building stage of DPI should be brought to an end. DPI's leadership training was aimed toward building leaders for organizations. It could be argued that since DPI had built organizations in some one hundred countries it should move on to other activities. It could be more involved in changing local and national living conditions for disabled people. DPI could do this through helping organize and fund locally-initiated socio-economic projects. Ultimately, DPI, in its three-year

²³ Neufeldt, et al., An Emerging Voice, pp. 35-37.

development program, 1986-1989, included planning for income-generating projects in its objectives. Approximately one-fifth of the program's funds were to go towards such projects.²⁴

C. SOCIO-ECONOMIC PROJECTS

Most organizations in DPI did not have any funding from government, especially those in the developing world. Many of the organizations were concerned about funds, not only to hire staff for the organization, but to better the lives of disabled people in their country. They started employment-creation and rehabilitation projects. DPI's Development Program had an indirect impact on the development of some projects between 1982 and 1985. It enabled disabled people to meet each other and share project ideas. For example, at the Barbados 1985 Training Seminar, people from Guyana, after talking with others who were running employment projects, became inspired to start their own. In 1986, the Guyana Coalition of Citizens with Disability started a hatchery run by disabled people.²⁵

But DPI did not always fulfill the expectations or needs of disabled people either. Some African leaders attended the 1984 DPI Symposium on Development in Jamaica, where development agencies and disabled persons met. They brought project proposals along, hoping to find an interested funding agency. Most people were disappointed, though, because many development agencies did not attend, and because most of the time was spent discussing philosophical issues. Some Africans expressed disappointment

²⁴ Disabled Peoples' International, "Economic and Social Cooperation: DPI Self-Help Training Program, 1986-1989," Winnipeg, 1985, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

²⁵ Interview with Henry Enns, DPI Chairperson, Winnipeg, Canada, Oct. 31, 1986.

that their disabled people had not benefitted financially from being affiliated with DPI.²⁶ DPI, however, did not view its role as one of finding funds for its members. Its focus was on providing contacts so that disabled people's organizations could find their own funding for projects.

Indeed, overall, DPI's influence was indirect in starting socio-economic projects. Ideas were refined at DPI seminars and meetings. But the groups themselves contacted funders in their countries and development agencies interested in working with them. The following examples were initiatives undertaken in different parts of the world.

In 1984, the National Council of Disabled Persons of Zimbabwe (NCDPZ) started an outreach program. Its purpose was to locate disabled people in the rural areas, to help them organize, and to start projects. First of all, the Council's outreach staff travelled in the rural areas and identified and talked to disabled people. In many cases, disabled people in an area would form small groups. These would become branches of the NCDPZ. The NCDPZ encouraged nondisabled persons to be involved too. There were no conditions for membership in the NCDPZ. It was open to those who supported the philosophy of the Council for disabled people to integrate into society, and to speak out on their own concerns. The outreach workers also did public education in the communities. They talked to village leaders, church people, doctors, government officials, and the peasants to convince them of the need to integrate disabled people.²⁷

²⁶ Zogo Menye Alphonse, Président, Union Nationale des Handicapés du Cameroun, to Jan Johnsson, Head of DPI Secretariat, June 24, 1986, Henry Enns, DPI Chairperson, Files, Winnipeg, Canada.

²⁷ Joshua T. Malinga, "The Silent Majority," in The Winds of Change: Partners in Development, Proceedings of the DPI International Symposium on Development 1-5 October 1984, ed. Diane Driedger (Winnipeg: Disa-

These groups continued to locate disabled people in their area and to encourage them to join. Many rural groups worked on small projects that helped them obtain skills and that brought in some revenue. The most popular projects were small animal and vegetable growing. Others did spinning, weaving and sewing. The Council headquarters staff raised funds to start these projects. Horticultural Therapy and Rural Training of England helped with its expertise in starting small agricultural projects. "HT is a specialist agency concerned with the promoting of agriculture, horticulture and rural crafts for disabled and disadvantaged people."²⁸ These projects meant that a disabled person was productive in the community and was integrated into its economic activities.

In Nicaragua, the Organization of Disabled Revolutionaries ORD ran a wheelchair workshop. There, disabled people built wheelchairs and crutches. It also started a sewing cooperative, where both disabled, and nondisabled people worked. Again, this provided employment for disabled people in an integrated environment.²⁹

Several groups began projects in the Caribbean. In fact, this area was the most productive in starting projects. Since 1981, the St. Lucia Council of the Disabled started a popsicle-making business, and a fruit drink business. The marketing strategy was to take advantage of opportunities: "In St. Lucia, the tourist industry is perhaps the second big money-making

bled Peoples' International [Canada] Inc.), p. 50.

²⁸ National Council of Disabled Persons of Zimbabwe, "Outreach Program Project," ca. 1984, p. 3, in author's possession.

²⁹ Coalition of Provincial Organizations of the Handicapped (COPOH) "Interview with Georgina Heselton, Saskatchewan Voice of the Handicapped, Info COPOH, (June, 1986), p. 2.

thing there. But are disabled people benefitting from it? The answer is no."³⁰ They found a market selling popsicles and fruit drink to tourists.

The Combined Disabilities Association (CDA) in Jamaica started a wood products factory that made toys and ornaments in 1983.³¹ It was staffed with 50% disabled, and 50% nondisabled workers. The profits from the factory were used to sustain the CDA's operations. It also benefitted the twenty disabled workers economically and in skills training. This project was assisted by volunteer staff, both from Mennonite Central Committee and CUSO. As mentioned earlier, the Guyana Coalition of Citizens with Disability decided, after attending the DPI Training Seminar in Barbados, to start a hatchery.

Disabled people in developed nations also started projects to benefit themselves. In Canada and the United Kingdom, independent living centers were founded between 1982 and 1985.³² These centers were based on the same premise as those started in the US in the 1970's. They were run by disabled people to help other disabled people to live as independently as possible in the community. Attendant care, peer counselling, and information

³⁰ Tony Avril, "Community-Based Projects in St. Lucia," in The Winds of Change: Partners in Development, Proceedings of the Disabled Peoples' International (DPI) International Symposium on Development, 1-5 October, 1984, Kingston, Jamaica, ed. Diane Driedger (Winnipeg: Disabled Peoples' International [Canada] Inc., 1985), p. 60.

³¹ Huntley Forrester, "Report on DEEDS Industries," in The Winds of Change: Partners in Development, Proceedings of the Disabled Peoples' International (DPI) International Symposium on Development, 1-5 October, Kingston, Jamaica, ed. Diane Driedger (Winnipeg: Disabled Peoples' International [Canada], Inc., 1985), p. 47.

³² April D'Aubin, ed., Defining the Parameters of Independent Living (Winnipeg: COPOH, Inc., 1985); British Council of Organizations of Disabled People, "Centres for Integrated/Independent Living, Prepared for BCODP AGM and Conference," September, 1985, in author's possession.

and referral about existing services were some of the features of the centers. Thus, the independent living centers provided information and services to help disabled people to live in the community and to participate like everyone else.

Both North American and European organizations of disabled people contributed to development projects in the developing world. In some cases, these projects were undertaken independently of DPI. The Norwegian Association of the Disabled provided funds for a meeting of organizations of physically disabled people in Africa.³³ Presumably these funds were obtained from the Norwegian Government. Likewise, HCK in Sweden has provided monies for the running of the National Council of Disabled Persons in Zimbabwe's office.³⁴

In Canada, two provincial chapters of the Coalition of Provincial Organizations of the Handicapped (COPOH), have "twinned" with organizations in the developing world. In a twinning relationship, organizations share expertise and resources for the benefit of disabled people in their countries. People United for Self-Help in Ontario (PUSH) in Kingston, Ontario, twinned with Jamaica's Combined Disabilities Association in 1984.³⁵ The Voice of the Handicapped of Saskatchewan twinned with Nicaragua's Organization of Disabled Revolutionaries in 1984. Saskatchewan sent wheelchair parts to Nicaragua. There were also exchange visits. Members of

³³ A. Eidhammer, "Disabled People Must Organize!" The African Rehabilitation Journal 2 (July, 1985), pp. 2-3.

³⁴ Joshua T. Malinga, "National Council of Disabled Persons of Zimbabwe, Chairman's Report to the Annual General Meeting held at Park Lane Hotel, in Harare on July 16, 1983," 1983, p. 1, in author's possession.

³⁵ Wayne Westfall, "Jamaica--And Its Disabled," CUSO Forum 2 (Nov., 1984), p. 4.

the Nicaraguan organization came to Canada in 1985.

In all, disabled people in the developed world felt a need to help others with fewer resources, but they also helped for philosophical reasons. Georgina Heselton of the Voice of the Handicapped of Saskatchewan explained:

It is important for the disabled to work together on an international level to build a broad movement. As Canadians we can get to know the hardships of disabled people in developing countries, but also the striking similarities between us, in the obstacles we face.³⁶

Indeed, the Swedes concurred with the concern for all disabled people:

It is our belief that disabled people will benefit from the exchange of information through the world network of DPI, as well as contributing to international solidarity by assisting sister organizations to build up in developing countries.³⁷

Other European countries, such as Finland, contributed directly to DPI Development Program efforts. The Kynnys r.y., (The Threshold), a group of disabled people in Finland, raised money from their government to support DPI's development activities.³⁸

Overall, disabled people mainly started socio-economic projects on their own without the direct input of DPI. They raised funds from development aid agencies and began their own self-sustaining projects.

³⁶ COPOH, "Heselton Interview," p. 2.

³⁷ Peter Lamming, International Secretary, DPI Sweden, to Diane Driedger, October 17, 1986, p. 2.

³⁸ "Acknowledgements," in The Winds of Change: Partners in Development, Proceedings of the Disabled Peoples' International (DPI) International Symposium on Development, 1-5 October, 1984, Kingston, Jamaica, ed. Diane Driedger (Winnipeg: Disabled Peoples' International [Canada] Inc., 1985).

D. OVERCOMING SOCIETAL BARRIERS

Generally, DPI was not involved directly in the lobbying efforts of national and local organizations. Disabled persons lobbied their governments, business, and the public for the elimination of the attitudinal and environmental barriers to their participation. The following were instances of their activities.

In Canada, the Coalition of Provincial Organizations of the Handicapped was successful in having the rights of disabled persons included in the federal Human Rights Act in 1983. In 1981, COPOH also lobbied the Government to have the rights of disabled people included in the new Canadian Constitution. Their rights were entrenched in the Constitution's Charter of Rights and Freedoms.³⁹

In Jamaica, the Combined Disabilities Association (CDA) undertook several successful awareness campaigns. It has done public education work about the abilities and rights of disabled people, mainly through a newsletter and a weekly radio show.⁴⁰ It negotiated with the government about housing options for disabled people in the community. This led to the government committing 5% of all new public housing apartments to be accessible to disabled persons. Down payments and interest payments were waived by the government in 1981 on the purchase of such units.⁴¹

³⁹ Diane Driedger, "Speaking for Ourselves: A History of COPOH on Its 10th Anniversary," in COPOH 1985-86 Annual Report (Winnipeg: Coalition of Provincial Organizations of the Handicapped [COPOH] Inc., 1986), p. 21.

⁴⁰ Westfall, "Jamaica," p. 4.

⁴¹ Combined Disabilities Association, "CDA Info Sheet," ca. 1984, p. 5, DPI Development Office Files, Winnipeg, Canada.

In Argentina, the Corporation of Disabled People (CADIS) has been conducting awareness sessions with the university architectural school in Buenos Aires.⁴² Their premise was that to create a physically accessible society, architects needed to be educated about physical barriers (such as stairs) and how to overcome them in architectural design.

In December 1981, the Government of Pakistan enacted the Disabled Persons Employment Ordinance. The Pakistan Association of the Blind had lobbied for this for ten years:

This ordinance, apart from other things, ensures 1% quota of jobs for the disabled in all public and private institutions in Pakistan, along with suitable training facilities for them.⁴³

In 1984, the newly-formed Disabled People's Federation of Pakistan, an umbrella organization of seventeen uni-disability groups, intended to lobby for a consultative committee of disabled people to help implement the ordinance.⁴⁴

In Nicaragua, the Organization of Disabled Revolutionaries (ORD) conducted a campaign to increase public awareness about the need for wheelchair accessibility. Transportation, in particular, was a problem for disabled people since buses were not accessible. They had steps. Taxis were the main transportation for disabled Nicaraguans. Many taxi drivers refused to carry disabled passengers because they did not want to bother helping a person transfer from the wheelchair into the car and then load

⁴² Interview with Jacqueline de las Carreras, DPI World Council Member, Kingston, Jamaica, Sept. 28, 1984.

⁴³ Dr. Fatima Shah, "Up-to-Date Report of World in South Asian Region," ca. 1984, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

⁴⁴ Ibid., p. 2.

the wheelchair in the trunk. ORD has been working with taxi cooperatives to end this discrimination.⁴⁵

The foregoing organizations, and others around the world, have been raising awareness with governments and the public about their accessibility needs. These have been almost entirely local and national efforts. These organizations were adept at using available resources, such as funds, leaders, strategies and tactics, and the DPI philosophy of disabled people speaking for themselves and engaging in self-help activities to bring about changes. DPI's contribution has been in creating international solidarity. Developed nations, in Europe and North America have helped in the projects of their disabled sisters and brothers in the developing world. DPI would do its main work on the international level through its Development Program and its international political involvements. DPI has also been successful in using its resources of leadership and funds for its Leadership Training Program. But, DPI needed to continue to build an organizational infrastructure to enable itself to confront issues at UN international forums and to be a philosophical resource to its membership. It had set out to create an organizational infrastructure after the Singapore Congress.

⁴⁵ Medical Aid to Nicaragua, "What is ORD?" 1985, p. 2, in author's possession.

Chapter VI

INTERNAL OPERATIONS, 1981-85

A. INTRODUCTION

Throughout the period 1981-85, DPI's internal operations and politics were characterized by five trends. First, the World Council was, in large part, a continuation of the old boys' Steering Committee network that excluded certain groups. The Steering Committee members were all elected to the new World Council, except one member, Gebels, from Australia. Half the Council, and all but one of the executive positions, were filled by the old Steering Committee members. Indeed, this group was, in a sense, an elite clique that held much of the power in DPI. The original Steering Committee had only one woman going into the Singapore Congress and no representative of the deaf or mentally handicapped communities. These groups had been underrepresented in Winnipeg at the RI Congress in 1980, where the Steering Committee was elected.

The power dynamics in the new World Council were affected by conflicts between executive members who knew each other in the Steering Committee stage. A battle between the visually-impaired and mobility-impaired also carried over from the Steering Committee in more acute form after the Singapore Congress. While DPI was a coalition pledged to include persons of all disabilities, disability groups tended to coalesce into blocs of influence. This tension was compounded by a rivalry between the Swedes and

Canadians. The Swedish national organization, HCK, tended to be dominated by people with visual impairments, while, within the Canadian COPOH, people with mobility impairments dominated at the decision-making levels.

Finally, amidst these points of tension, the leadership of DPI struggled to initiate a new international infrastructure. Most of those involved were relatively inexperienced at international organization building. All of the foregoing factors affected the operations of DPI as an organization. Often they proved disruptive and many of the Council meetings of the organization were preoccupied with political manoeuvrings and power struggles within the organization. This dissipated energies and resources that DPI could have expended outside the organizational infrastructure to challenge societal barriers. The following sections explore these five trends.

B. WORLD COUNCIL

1. COMPOSITION

The World Council elected in Singapore included all the Steering Committee members except Gustav Gebels. Thus, ten of the Steering Committee members returned to power. There were twenty-two Council members in all. Certain regions, such as North America and Europe, did not have a full complement of five members on the Council. This was due to the European Region having only three representatives of self-help groups in Singapore when the Council was elected. Also, only four countries from the North American/ Caribbean region were represented in Singapore. The inadequate representation of these regions in Singapore was partly due to disabled people from the developed regions being ineligible for DPI sponsorship.

Many disabled people from developed countries could not afford to travel to Singapore and were unable to raise money on their own to attend.

The World Council included five women. Africa did not have a woman on the Council. The ages of these members were thirty-five to sixty-six years old, with the greatest proportion of people being thirty-five to forty-five years old. The disabilities represented on the Council were seventeen mobility-impaired people, six blind people, and one deaf person.

2. POWER DYNAMICS

While mobility-impaired men were greatest in number on the Council from 1981 to 1985, the blind persons' group was stronger than its numbers indicated. This was due to several factors. Two key players in the Steering Committee, Chandran-Dudley of Singapore and Lindqvist of Sweden, became Chairperson and Secretary respectively, of the new Council. They had previous international experience with Rehabilitation International and the International Federation of the Blind. Thus, they had credibility and influence within the disabled people's movement and in the Council. The remaining three executive members, Enns, Deputy Chairperson, Malinga, Treasurer, and Saeboenes, Publications and Information Secretary were mobility-impaired.

In the subsequent functioning of the Council, at its four World Council meetings in Japan, Sweden, Jamaica and Bahamas, blind people tended to support one another within the World Council. The same was true for mobility-impaired people. Thus, two camps were mobilized within the Council. These conflicts did not bring the activities of the organization to a halt. But the conflicts slowed down the implementation of activities due

to poor communications. The conflicts led to a siege mentality on both sides. The Swedish/Canadian rivalry, and the conflicts between two executive members, one blind and from the developing world, and the other mobility-impaired, and from the developed world, caused difficulties in the functioning of DPI.

3. EXECUTIVE CONFLICTS

Conflicts existed between two executive members around three issues: the differences in the perspectives of the developing and the developed worlds, leadership style, the World Congresses, and the administrative offices in Canada and Sweden. All these issues contributed to an atmosphere of distrust in the internal operations of DPI.

First, to some extent, the conflict between the two executive members was exacerbated because one was from the developing world and the other from the developed world. There was some belief on the part of the developing world person that the developed world disabled people, including the other executive member, had more access to monetary resources and because of this they had control of the "pursestrings" for DPI. On the other hand, the developed world executive member and World Council members believed they were handling the money they received as equitably as possible. This differing point of view served, to some extent, as a backdrop to the executive members' conflicts on other DPI issues.

Second, leadership styles clashed from the first meeting of the Council in Singapore. Members of the World Council felt leadership style was reflective of DPI as an organization. On the one hand, some members of the World Council preferred one person leadership through the Chairperson.

They felt that strong leadership from the Chairperson showed that the organization was behind that person and knew where it was going. The Chairperson, in essence, embodied the organization at different international functions and in the media. Other people within the organization felt that DPI should personify collective leadership. Namely, those persons on the executive should take direction from the grassroots of the organization and implement its needs and desires. The function of the Chairperson in a collective leadership model was to coordinate the efforts of the grassroots, the regional councils, and the members of the World Council to better the situation of disabled people around the world.

Thus, at the World Council meetings, 1982-85, there were conflicts between these two perspectives. If the members' perspectives on leadership had been similar, the Council meetings would have run more smoothly. The leadership style debate heightened the level of mistrust involved in reporting on the Singapore Congress, and in the planning for the World Congress in Bahamas in 1985. The mismanagement of these two issues damaged DPI's credibility with the United Nations, international funders, and with the disabled people's constituency to some extent.

B. WORLD CONGRESSES: SINGAPORE AND BAHAMAS

Two World Congresses were held during the period 1981-85. They were different in character. The Singapore Congress served to add momentum to the DPI movement, while the Bahamas Congress was poorly organized and thus drained energy from the membership.

According to the DPI Constitution, a Congress must be held every four years. The World Congress was not a policy-making body, rather it was a

forum for discussion of pertinent issues for disabled people and their organizations. The First World Congress of DPI in Singapore, however, was a policy meeting. It was held to accept the Constitution, Manifesto, and Plan of Action for DPI. However, it was agreed in the World Council, and stated in the Constitution, that subsequent Congresses would not make policy. Rather, they would be forums of discussion to give the World Council ideas about which issues were important to disabled people. These Congresses were open to any disabled people who wanted to attend, as well as to representatives of international and national bodies, such as UN organizations and international aid agencies, who were interested in DPI.

There was a problem of representation at the Singapore Congress. Delegates were chosen in a haphazard manner to attend the Congress. People that the Canadian office sponsored were mainly from disabled people's organizations, but in some cases they were not. They were individuals wishing to attend. Some who attended and were elected to World Council were later found to be corrupt (to have misused their organizations' funds), or were not representative of the self-help group in their country.

Overall, though, the Singapore Congress was a resounding success when measured by enthusiasm and the momentum it gave organizations of disabled people around the world. But difficulties over the reporting for the Congress arose soon after in 1982. It was decided in Singapore at the first World Council meeting, that Michigan State University's University Centre for International Rehabilitation would edit and publish the proceedings of the Singapore Congress. Indeed, the University Centre would foot most of the cost in putting out the report in book form. The editors of the proceedings attempted to obtain copies of all the papers presented, but their

letters were not heeded. Thus, they decided to include all the papers they had and to write summary chapters about the events, people and atmosphere of the Congress. It was not a typical conference proceedings. Rather, it was to be a tool for inspiring disabled people to organize.¹ And when the report appeared in the fall of 1982, it looked very professional and was well-edited. This was only on the surface, however, as several World Council members were disturbed about the portrayal of several events in the report. First, they felt that the presentation of the political conflicts over the representation of China showed a naivete about world events. Second, some World Council members believed that a commentary on the conflicts involved in the constitutional battle, which ensued about definitions, was inappropriate. The Council decided the report was not the official report of the Congress.² It was decided that DPI would publish an official proceedings for the Congress on its own. This was undertaken, and in 1985 the English report of edited papers was published. French and Spanish versions were still waiting to be printed.

The disagreements over the appropriateness of the Congress report caused problems for funders and hurt the international credibility of DPI. Several funding agencies which had supported the Singapore Congress have since not granted any more funds to the organization. These organizations felt that they should see a final report and a proceedings of this Congress before they would grant additional money.

¹ Kathleen S. Miller, University Centre for International Rehabilitation, Michigan State University, to Liam Maguire, Ireland, Dec. 10, 1982, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

² Disabled Peoples' International, "Minutes of the DPI World Council Meeting, Stockholm, Sweden, August 15-25, 1983," pp. 10-11, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

The controversy surrounding the report can be chalked up to the inexperience of the fledgling DPI in producing such reports. Indeed, the final draft was not circulated to all the World Council members before it was published.

After the Singapore Congress, there were problems with the film that was made with funds from the Japanese Shipbuilders Foundation. The film was put together, and some of the Council members saw it. They were not pleased with the editing job done on the film. They decided that it could be done better in Sweden. The Swedes took a year to produce a new film. Again, the impact of the Singapore Congress was lost. Also the film produced in Sweden turned out to be a promotional film for DPI, discussing its philosophy, goals and objectives for the future, rather than the happening of the Singapore Congress. Some of the World Council members were unhappy that the momentum of Singapore had been squandered.

In the planning for the Bahamas World Congress for 1985, difficulties were also encountered. Again, planning for the event only began four months before it was to be held. This was due to the lateness of accepting the Bahamian group's offer to host the World Congress. As late as the World council meeting in Jamaica in September 1984, the decision still had not been made. This was due to the two executive members disagreeing about where the meeting should be held. One member supported Bahamas, while the other wanted it held in Vienna, closer to UN offices. Others in the organization felt the Disabled Persons Organization in Bahamas was too new, small and inexperienced to host such a major event. But, there were questions too about whether the disabled people's organization in Austria would be any more experienced than the Bahamians.

By the end of the World Council meeting in 1984, however, the Bahamian Disabled Persons Organization was asked to be the next hosting organization of the World Congress. The actual planning for the meeting only began in the spring of 1985 when the Bahamian group formed an organizing committee. Fund-raising for an international subsidy program also began in 1985. DPI emerged from the Congress with a deficit. There had been little time for local fund-raising in the Bahamas. Furthermore, the Congress accommodations, transportation and program were disorganized. Many people felt frustrated at this disorganization. Some felt that the lack of coordination interfered with discussing issues of concern to disabled people. Some representatives of governments, UN, and development agencies felt the same way. This hurt the credibility of DPI once again.

The United Nations again promised monies and delivered them during and after the World Congress, as in the case of the Singapore Congress. This time it caused suffering for disabled Africans. Many Africans did not receive their tickets in time to attend. Others borrowed money to buy tickets and were reimbursed after the Congress. All of this caused anxiety in those delegates sponsored by DPI.

From these experiences the Council realized that planning for the next World Congress in 1989 must start as soon as the 1985 Congress was finished. They realized that staging an international event required enormous energy on the part of the DPI offices and the local organization. Sufficient time was needed to raise funds and to arrange local accessible travel and accommodation for disabled people. Organizing an international conference was a feat for any organization. But logistics for disabled people included extra planning to guarantee accessibility of facilities and support services, such as attendant care.

C. ADMINISTRATIVE PROBLEMS

The inexperience and disorganization reflected at the Bahamas World Congress characterized the DPI administrative offices, 1981-85. Again, these growing pains were a function of building a new international infrastructure. But the conflicts between the two executive members also affected the functioning of the organization. It contributed to poor communications between the two main DPI offices in Canada and Sweden. Also evident in the relationship between the offices was the deepening rivalry between the Canadians and the Swedes. There was one office in Canada, responsible for development projects, and there was another in Sweden, which was the head Secretariat. The Swedish Secretariat handled membership matters, internal communication and external communication with the UN and international bodies.

Misunderstandings often arose between the two offices concerning their roles in the organization. They also wondered whether information was being shared between the offices openly. The misunderstandings had their roots in the Singapore World Council meeting in 1981. It was decided that Canada would continue to retain the secretariat of the organization for six months. This was decided because Canada had current resources to continue the secretariat's function. They also agreed that the new location of the secretariat would be decided at the next World Council meeting.³ This understanding about who would take on the secretariat function was not clear to everyone in the organization. The Secretary of DPI was Bengt Lindqvist from Sweden. Thus there was an assumption on the part

³ Disabled Peoples' International, "Minutes, World Council Meeting Dec. 4, 1981, Singapore," p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

of some Council members that the secretariat of the organization should be in the country where the Secretary himself resided. Because of this confusion, from December 1981 to the next Council meeting in Tokyo in June 1982, there was some conflict between the office in Canada and the Swedes. In Spring 1982, the Swedes received funding for a secretariat in Stockholm. There was pressure from some World Council members to start moving the secretariat functions of the organization to Sweden before June 1982. At the same time, funding for a program from the Canadian International Development Agency seemed quite likely by the Tokyo Council meeting in June. Thus, the Canadian office would become the development office. For many people it followed that the Swedes would take on the Secretariat function.

In the meantime, both offices suspected the motives of the other. This included a belief that the other office was hoarding and keeping information about what was happening in DPI. This was compounded by the fact that the Steering Committee Secretariat had been in Winnipeg, and thus the Canadians felt a sense of ownership. Furthermore, while the Swedes had promised in 1980 to fund a Steering Committee secretariat in Sweden, it never materialized. At that point, Enns stepped in to create the Canadian secretariat. Therefore, the Canadians were disappointed in the Swedes. In the end, the Swedes took over the secretariat function for DPI. And the Canadians took over the development office function.

The feelings of mistrust were in many ways precipitated by the rivalry between the two executive members, who aligned themselves with one or the other of the offices. The mistrust meant that the offices did not keep each other informed of their activities. Copies of letters were not

shared regularly. There was also a reluctance to talk on the phone to those they felt uncomfortable with. This siege mentality continued until the Bahamas World Congress in 1985. Only time would tell whether the election of a new World Council and Executive at the Bahamas Congress would serve to heal these wounds.

The decision to have two main offices came about largely as a result of funding bases in Sweden and Canada. As mentioned earlier, CIDA granted a sizeable sum of money to the development office. This funding was contingent on the office remaining in Canada. Likewise the Swedish Government granted most of the funds for the DPI Secretariat from 1982 to 1985. The total amount of money granted to the Secretariat has been \$417,462 (US).⁴ The ongoing commitment of the Swedish Government for this office was \$110,000 per year. In addition, it paid 90% of two support staff salaries, totalling some \$23,000 a year. The Deputy Chairperson has been responsible for the Development Office. The Secretariat in Sweden has been responsible to the Honorary Secretary of DPI.

By 1985, DPI had a combination of charismatic and rational-legal leadership. Although the charismatic leaders in the World Council still made the decisions and set the goals of the organization, some rational-legal leaders were involved. The two offices hired staff to carry out the daily operations of DPI. Up until this point, DPI had had temporary staffing arrangements through Derksen and Driedger. They had been hired to organize the Singapore Congress.

⁴ Disabled Peoples' International, "Simulated Statement of Revenue and Expenditure for the Combined Canadian and Swedish Operations for the Year Ended 31 March 1985," in "Disabled Peoples' International, "Minutes World Council Meeting the Bahamas, Sept. 15-17, 1985," Disabled Peoples' International Development Office Files, Winnipeg, Canada.

A combination of leadership types is characteristic of social movements in general. According to Mauss:

As a social movement grows and develops, it is increasingly likely to generate voluntary but formal organizations (e.g. Common Cause), sometimes even with salaried staffs, to carry on the work full-time. Those social problem-movements which involve such formal organizations as part of their strength and support will include leadership of the rational-legal type, frequently along with individual charismatic leaders.⁵

D. UNDERREPRESENTED GROUPS

During the period 1981-1985, the month-to-month functioning of DPI, in large part, was directed by the administrative offices and the executive. Again, the people involved were mainly those who had initiated DPI. The World Council, however, met once a year to make policy decisions for the organization. In this group deaf people, women, youth, and mentally and psychiatrically handicapped people were underrepresented, or not represented at all. Deaf people and women both found themselves in situations of relative deprivation within DPI. They expected that an organization concerned with the rights of all disabled people, regardless of disability or gender, would be concerned about their representation and role in decision-making. DPI, however, fell short of their expectations. Both a deaf person's representative and women asserted their right to be heard and to have an equal role in the organization.

⁵ Armand L. Mauss, Social Problems as Social Movements (Philadelphia: J.B. Lippincott Co., 1975), pp. 53-54.

1. DEAF PEOPLE'S PARTICIPATION

There were few people with hearing impairments at the First World Congress in Singapore. No deaf people were elected to the World Council from any of the regions. Therefore, after the Singapore Congress the Asia/Pacific region decided to coopt a deaf woman, Manfa Suwanarat, from Thailand, to the World Council. Throughout the years that she sat on the Council, there were difficulties encountered with educating the Council about the needs of a person with a hearing disability. Other Council members had mobility or visual impairments. They understood that people who were profoundly deaf, as was Suwanarat, required sign language interpreters to understand the meetings. In Tokyo in 1982 Suwanarat brought one interpreter who was paid for by DPI. The interpreter was her key to understanding and communicating with everyone during the meetings. She and her interpreter found that one person to interpret the ten days of meetings was insufficient. He became very tired due to interpreting sixteen hours a day.

Thus, at the Swedish World Council meeting in 1983, a resolution was presented at the meeting calling for two sign language interpreters for any deaf world council member. It was agreed that funds would be raised to bring those two people with the deaf person. Suwanarat knew Thai sign language. It was not acceptable to hire interpreters in the country where the meeting was because they had a different sign language. Sign languages in different countries were totally different languages. There was no international sign language. The national sign language of a deaf person was very important to the culture of the deaf person.

The question of deaf people's participation in DPI still remained a burning one after the 1985 Bahamas World Congress. There were few deaf persons in attendance at the Congress. In fact, those who were represented were mostly local deaf people from Bahamas. The new World Council did not include a person with a hearing disability. The task of recruiting members of the deaf community into national organizations of disabled persons, and into DPI, still remained a crucial task for the future.

2. WOMEN'S CONCERNS

Women's involvement in DPI from its beginnings has been minimal. Only one of the original Steering Committee members was a woman. Five women were represented on the twenty-one member World Council of DPI, the governing body, from 1980-85. Only two women were elected to the new World Council for 1985-1989. Out of 250 delegates to the Congress some seventy-five were women. The developing regions had very few women attending. For instance, there was only one woman from Africa out of twenty African delegates. Disabled women's concerns first arose at the World Council meeting in Stockholm, Sweden in 1983. Women with disabilities were not well-represented on the World Council at the time, nor on the Regional bodies of the organization. Therefore, in Sweden a resolution was put forward calling for more women

to be involved in the organization of disabled people on local, national, regional and international levels and that they should be included in all national, regional and international delegations in order to provide them with an opportunity of acquiring experience and knowledge to improve their situation.⁶

The women's question was not resolved at that point.

⁶ DPI, "Minutes Swedish World Council Meeting, 1983," p. 14.

A year later at the World Council meeting another resolution concerning women's participation came forward. It resulted from women's meetings held outside the regularly scheduled sessions of the meeting. At the women's meetings the participants expressed concern that there were few women involved in the executives and governing bodies of national organizations of disabled people. They also expressed concern that there were few women involved in the decision-making bodies of DPI. The resolution called for measures to include women on executive bodies and national councils in DPI member countries. It stated "the ultimate goal of this process is to bring the percentile representation of women on national councils to 50%, in accordance with their representation in the population."⁷ The resolution called, further, for leadership training seminars focussed on women with disabilities only to be held.

At the Second World Congress of Disabled Peoples' International (DPI), September 18-22, 1985, disabled women met to discuss their concerns about equal representation. They presented a resolution to the organization requesting 50% representation in its decision-making structures.

The largest delegations of women at the Congress were from Canada and Australia. Both these countries had a majority of women in their delegations. The Canadian and Australian women played important roles in raising the issue of women's representation. They arranged meetings outside the scheduled Congress sessions, to which they invited all women with disabilities. Some sixty women met and shared information about the partici-

⁷ Diane Driedger, ed., The Winds of Change: Partners in Development, Proceedings of the Disabled Peoples' International (DPI) International Symposium on Development, 1-5 October, 1984, Kingston, Jamaica (Winnipeg: Disabled Peoples' International [Canada] Inc., 1985), p. 72.

pation and representation of disabled women in their countries. They agreed that disabled women had difficulties in speaking out in disabled peoples' organizations that were largely controlled by men; many women lacked the confidence to speak out at meetings where men were present and tended to dominate discussions. For example, men tended to dominate the Congress plenary floor. At the women's meetings, however, many women felt comfortable to speak out. Other issues were discussed such as the lack of marriage opportunities for disabled women in the developing world, where marriage and family were often the only source of status for women. Disabled women were not seen as sexual beings by societies because their bodies were not perfect.⁸

After the first meeting, the women struck a committee to draft a resolution for equal women's participation in DPI. By the end of the week-long Congress, the resolution was presented on the plenary floor. During its presentation, Dr. Fatima Shah, of the drafting committee, warned that disabled women could separate from DPI, just as DPI had from Rehabilitation International five years earlier. Indeed, the rising expectations of the women had been frustrated since 1981. There had been little movement on DPI's part towards including more women in decision-making or in leadership training. The women threatened to form their own movement to combat their perceived deprivation in these areas.

The World Council of DPI met and passed the resolution. It proposed that five women be coopted, or appointed, to the World Council, one from each of the five regions of the world. The resolution also called for the

⁸ Diane Driedger, "Women with Disabilities Meeting," in "Notes on the Sessions of the DPI Bahamas World Congress," Winnipeg, Canada, Sept. 18, 1985, in author's possession.

increased representation of women, up to at least 50% at the regional and national levels of the organization. To aid in this process, the resolution proposed that leadership training seminars be held for women in the developing regions through DPI's Development Program. During the period 1982-1985, nine seminars had been held, but the majority of participants had been men. Disabled women wanted seminars aimed at their own concerns and needs.⁹

In addition to these measures, the DPI World Council elected Dr. Fatima Shah of Pakistan as Chairperson of the newly-created Standing Committee on Women's Affairs. The Committee was to monitor implementation of the resolution. It would attempt to keep women informed about what disabled women in all regions were doing to address their concerns.

There were varied responses to the women's agitation for more participation in the decision-making bodies of Disabled Peoples' International. A few women were not involved in the women's meetings. They seemed to believe that feminism should not be aired at a Congress on disability. Some felt they did not want the Congress to be seen as speaking out only on women's issues. They wanted DPI to be viewed as being concerned with all disabled people's issues.

Men from developed Western countries tended to acknowledge the legitimacy of the women's concerns. Some men spoke out on the floor in favor of the women's demands. The new Chairperson, Henry Enns was asked during his campaign speech for chairperson what he would do for women and what his

⁹ "Appendix 2, Resolution Adopted by the World Council Concerning Women's Issues, Sept. 23, 1985," in "Minutes of the World Council Meeting, Nassau, Bahamas, Sept. 23, 1985," Disabled Peoples' International Development Office Files, Winnipeg, Canada.

record had been on women's issues. He stated that he had worked for women at home in Canada. He claimed this was indicated by the majority representation of women on the Canadian delegation to the Congress. Another man from the North American region, though, described the demands of the women at the Congress as a "tempest in a teapot."¹⁰

There was mixed reaction from developing world men as well. At a plenary session, a man from Asia asked the "women to keep reminding us of your rights. I have a mindset that I have developed not to think of them." Several men from Latin America affirmed that women had an integral role to play in society. But, their remarks were met with boos when they stated that "behind every great man is a great woman." When the resolution for more women's participation was introduced on the floor some Africans abstained from voting. The resolution in favor of exploring measures for more participation was unanimous otherwise.¹¹

The women's issue was a difficult one for African men, who often still regarded women as wives whom they owned and who did their bidding. Women had few rights in many African societies. For example, children automatically became the property of the father. This was slowly changing though. For example, in Zimbabwe, a new family law gave women more rights over their children than they previously had. In fact, Africans were beginning to realize that women must be involved more in the African disabled people's organizations so that they were representative of all disabled persons.

¹⁰ Driedger, "Notes," Sept. 18, 1985, pp. 4-5, and Sept. 20, 1985, pp. 1-10.

¹¹ Ibid., Sept. 20, 1985, pp. 1-10, and Sept. 21, 1985, p. 1.

E. ORGANIZATIONAL ISSUES

While there were conflicts and representation difficulties, there were also housekeeping duties for DPI. Constitutional and membership issues were debated and decided upon in the period 1981 to 1985.

1. MEMBERSHIP ISSUES

Fifty-one countries were represented at the Singapore Congress, and some fifty-eight countries attended the Bahamas Congress in 1985. In fact, by 1985 there were officially fifty-one members of DPI. These members were national organizations of people of all disabilities.¹² At the time DPI had contacts in fifty other countries. DPI's membership included few countries from Europe and no countries from communist or socialist nations. Complications over the representation of China in Singapore probably set back Chinese membership. DPI as an organization, however, affirmed that it wished the People's Republic of China to be a member of DPI, not Taiwan. This was what the UN had done as well. The Chinese disabled people's organizations have been cautious about joining DPI, although they have been interested in the organization.

There was also controversy regarding South Africa's membership in DPI. This arose at the World Council meeting in Jamaica in 1984. The World Council was split on the issue of South Africa's membership. On one hand, Vic Finkelstein of Britain, formerly an anti-apartheid activist in South Africa, was against South Africa's membership. He believed that DPI should not accept its membership while apartheid was still in existence.

¹² Disabled Peoples' International, "Minutes World Council Meeting, the Bahamas, Sept. 15-17, 1985," p. 3, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

On the other hand, some Africans, such as Joshua Malinga of Zimbabwe, believed that South Africa should be allowed some type of affiliation with DPI. Malinga explained that the South African federation of disabled people included both black and white people in its membership. Furthermore, he argued, DPI should include South Africa because disabled people there were experiencing the same difficulties as disabled people in other parts of the world. And in fact apartheid created especially harsh conditions for black disabled people. The issue was hotly debated, and in the end DPI decided it would not welcome the participation of South Africa in DPI while the current system of apartheid existed.¹³

2. CONSTITUTIONAL CHANGES

The World Council had the responsibility of enacting the constitutional amendments that were agreed on at the Singapore Congress. When the Council met in Tokyo in 1982, amendments to the Constitution were discussed. The two major changes involved the definitions of disability and handicap. The original DPI constitution accepted the World Health Organization's (WHO) definitions of disability and handicap. Many of the World Council members and people at the Singapore Congress did not agree with these definitions. They reflected a traditional, medical model view of disability, handicap and disabled people. It was decided in Tokyo that a new definition would be substituted for WHO's definition in the Constitution. Again, disabled people redefined the social problem of disability, according to Mauss' model. They asserted that the physical and social environment handicapped their participation in society, not their own disabili-

¹³ Disabled Peoples' International, "Minutes of the World Council Meeting in Kingston, Jamaica, Sept. 24-27, 1984," p. 8, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

ties.

The definition adopted in Tokyo stressed that handicap was a relationship between an individual and his/her environment. This definition did not blame disabled people for their lack of participation in society. The definition as accepted was as follows:

a. Disability is the functional limitation within the individual caused by physical, mental or sensory impairment, and b. handicap is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers¹⁴

DPI's wanted these new definitions incorporated in international documents relating to disability, especially at the United Nations. It believed that when a minority group had its own definition of itself accepted, it had won a basic step toward self-determination for the lives of its membership. Disabled people had defined who they were. They wanted the world to accept their definition. They wanted society to cease to blame the disabled individual for his/her lack of participation, and instead blame the barriers society had erected. These barriers were paternalistic attitudes, and physical inaccessibility to the goods and services the rest of the population enjoyed.

Generally, then, DPI experienced internal conflicts and some mismanagement in its operations. The mishandling of resources such as leadership, membership and its World Congresses hurt DPI's credibility with some of its members, deaf people and women, possibly only in the short term. And its credibility with other organizations was hurt to some extent. But, overall, DPI's credibility continued to be bolstered by its strong repre-

¹⁴ Disabled Peoples' International, "Constitution," 1985, p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

sentations at international policy-making forums, as will be discussed in the next chapter.

Chapter VII

INTERNATIONAL ACTIVITIES

A. INTRODUCTION

DPI was concerned with four key issues in its representations to international forums. First, disability definitions were a DPI concern in the drafting of international documents and in meetings on disability, 1980-85. The debate over definitions was carried out at the meetings on the UN World Program of Action Concerning Disabled Persons and at the International Labor Organization's (ILO) meetings on a Vocational Rehabilitation Convention and Recommendation. Again, at these meetings DPI's concern with the definition of "disability" and "handicap" reflected Mauss' concept of redefining a social problem. Disabled people rejected the medical definition of themselves and instead believed that the physical and social environment excluded them from participation.

Second, DPI was concerned that disabled people's self-help groups be recognized as consultants on disability issues by the UN and governments. DPI held that disabled people best knew their own needs and concerns. Recognition for DPI included gaining consultative status with the UN Economic and Social Council (ECOSOC), the United Nations Educational, Scientific and Cultural Organization (UNESCO), and the International Labor Organization (ILO). Third, DPI, with consultative status, would have the ability to influence the outcome of these issues at the UN. DPI participated at the UN Human Rights Sub-Commission under this status.

Fourth, peace was an important issue for DPI. It called for funds spent on the arms race to be re-directed towards socially useful purposes.

B. DPI INVOLVEMENT AT THE UNITED NATIONS

DPI had two goals at the UN from 1981-85. First of all, it wanted to gain consultative status with the Economic and Social Council and with other UN bodies, such as UNESCO and the World Health Organization (WHO). Consultative status enabled non-governmental organizations to make presentations at UN meetings. It also meant that the UN organizations would consult DPI on international issues related to disabled people.

DPI attended UN meetings in order to gain credibility for itself as a powerful voice of disabled people that should be consulted on disability matters. With credibility at the international level, DPI influenced UN policies regarding disabled persons. Most importantly, DPI could define the needs and desires of disabled people internationally. It was the rightful voice of people with disabilities.

1. CONSULTATIVE STATUS WITH ECOSOC, UNESCO AND WHO

DPI obtained Consultative Status with the United Nations through its Economic and Social Council on May 12, 1983.¹ There were several international arms of the UN, of which ECOSOC was one. Under ECOSOC there were UN agencies, such as the United Nations Children's Fund (UNICEF) and the United Nations High Commissioner for Refugees. DPI prepared an application for consultative status stating how it could provide advice to, and

¹ Virginia F. Saurwein, Chief of Unit, Non-Governmental Organizations Unit, Dept. of International Economic and Social Affairs, to Henry Enns, May 16, 1983, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

cooperate with, the programs of the UN and its related agencies.²

Ron Chandran-Dudley, DPI Chairperson, and Henry Enns, Deputy Chairperson appeared before the Committee on Non-Governmental Organizations at the UN in New York. DPI applied for "Category I" the highest degree of status. At the Committee meeting on February 10, 1983, all members of the Committee recommended Category I status for DPI, except France and the USSR. Their feeling was that DPI was a very young organization.³ The USSR was also concerned that much of its funding came from governments. The USSR felt that DPI was only concerned about one area of ECOSOC activities, disabled people. DPI replied that it was concerned about a whole range of human activities.⁴ These would be issues of war and peace, occupational safety and malnutrition. Other countries agreed that DPI was concerned about many issues. But, the nineteen member committee needed unanimity to approve Category I, and thus Category II was granted instead. This was a disappointment. Category II meant DPI could not bring up new agenda items at UN meetings. Category II, however, still guaranteed DPI representation at the UN headquarters in New York and to UN offices in Geneva and Vienna. DPI also received UN documents and newsletters, and was allowed to comment on international issues at the UN and meetings of its bodies.

² Disabled Peoples' International, "Application for Consultative Status with ECOSOC," May, 1982, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

³ Ron Chandran-Dudley and Henry Enns, "UN Report," Winnipeg, 1983, p. 2, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

⁴ Ibid., p. 3.

The United Nations Educational, Scientific, and Cultural Organization (UNESCO) granted DPI Consultative Status, Category "C", August 6, 1985. This meant that DPI and UNESCO would share information with each other.⁵ Category C was the lowest degree of relationship. DPI could be an observer at meetings and express its views to UNESCO, but it could not vote at UNESCO meetings. Category A would give an organization the right to present proposals, vote and speak. In Category B an organization could vote and speak. By 1985 DPI had not attained a higher category. It usually took organizations several years to be elevated to a higher level.⁶

In May, 1985, DPI applied for consultative status with the World Health Organization (WHO). DPI and WHO had had informal discussions before then on various disability issues, and WHO representatives had taken part in DPI seminars and Congresses. No decision had been made by the end of 1985. The WHO process for gaining consultative status was that an organization and WHO needed to work together in informal consultations for several years.⁷

DPI consulted on several of WHO's projects. It had input into the World Health Organization's manual, Training the Disabled in the Community. The first draft of the manual was issued in 1979 and distributed for field testing to evaluate its effectiveness. In 1980, the manual was amended after consultation with disabled people, rehabilitation and community health people. The manual continued to be tested from 1979-1982, in

⁵ Amadou-Mahtar M'Bow, UNESCO, Director-General, to Ron Chandran-Dudley, DPI Chairperson, August 6, 1985, in author's possession.

⁶ Interview with Jan Johnsson, Head of Secretariat, DPI, Winnipeg, Canada, July 23, 1986.

⁷ Ibid.

such countries as India, the Philippines, Sri Lanka, Mexico and St. Lucia.⁸ The community-based rehabilitation (CBR) program aimed to provide disabled people in developing countries with education, jobs, and involvement in community life:

CBR promotes community responsibility and reliance on local resources. Family and community members take care of the essential training for their own disabled, using local technology...The community with its leaders takes on the responsibility for making necessary changes in the physical environment in order to give the disabled freedom of access. It also takes on the responsibility of positively influencing societal attitudes to further the acceptance of the disabled as equals.⁹

The program introduced local people to a training package that helped the community and families to enable disabled people to live more independently in the community. The program was largely successful, as 73% of the disabled people benefitted from training from 1979 to 1982 in nine countries.¹⁰ The CBR approach was taken due to the fact that only 2% of the disabled population received institution-based rehabilitation in the big cities. Most disabled people, who lived in the rural areas, received no physical rehabilitation, aids, or vocational training. Thus, the goal was to move away from building large buildings and toward keeping disabled people in the community with their peers.

DPI also agreed with the WHO study that services should be provided for disabled people to remain living in their communities. Large residential institutions, DPI believed, were a relic of the past. Independent living

⁸ Gunnel Nelson, World Health Organization (WHO), "Community-based Rehabilitation," "DPI Seminar Turku, Finland, August 21-24, 1983 Report," Stockholm, p. 2, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

⁹ Ibid., p. 1.

¹⁰ Ibid.

was the wave of the future. DPI has recommended that parents must be involved in training. Disabled persons themselves must be employed as teachers in CBR programs. It was disabled people who best knew the difficulties of other disabled people through their own experience with disability. In fact, DPI encouraged the CBR program to involve national and local disabled persons' organizations in its implementation.¹¹ The DPI consultation process with WHO has been mutually beneficial. WHO asked DPI, in fact, to write a chapter in the manual on how to build, and the importance of building, organizations of disabled people.¹²

2. WORLD PROGRAM OF ACTION CONCERNING DISABLED PERSONS (WPA)

DPI also raised its international credibility during the drafting of the World Program of Action Concerning Disabled Persons (WPA), 1981-83. The WPA was to be the UN's official statement on disability, and it would call on governments of the world to implement its recommendations. DPI pushed for new definitions of disability and handicap, and for organizations of disabled people to be recognized as the voice of disabled people. It was largely successful in having its views incorporated in the WPA.

It was initially to be drafted for 1981, the International Year of Disabled Persons. But, in 1980, the twenty-three country UN Committee assigned to draft the document realized it needed to be redrafted again. Thus it would not be ready for the 1981 International Year. The Committee was persuaded to include the principle of disabled people's organizations being consulted on disability matters. This task was aided by the par-

¹¹ DPI, "Report From Drafting Committee 1983-08-24," in "DPI Turku Seminar Report," p. 8.

¹² Johnsson Interview.

ticipation of Henry Enns, as an observer from DPI, and as an advisor to the Canadian delegation. The presence of Frank Bowe, a deaf man from the US, and Bengt Lindqvist, a member of the Swedish delegation, also aided the process. Indeed, it would seem that the presence of these disabled people had an impact on the shaping of the WPA.

The WPA incorporated significant principles for disabled people. The first draft, in 1979, put more emphasis on medical rehabilitation, and on the medical model that disabled people needed to be cared for all their lives. A draft was discussed at the 1980 RI World Congress in Winnipeg. Many disabled people took part in these discussions, and criticized the document. They wanted to change its framework and philosophy.

Ultimately, in 1981, a drafting committee was struck to redraft part of the WPA. Enns, LeBlanc of Canada, and Jim Crowe from the Canadian Embassy in Vienna were on the drafting committee. The Swedes and Canadians lobbied for it with other member countries. "The concepts of consumer involvement, consultation, and support for organizations of disabled people were clearly in evidence in this first draft."¹³ Between the meetings in 1981, and when the Committee met again July 5-14, 1982, the members of the twenty-three countries shared the WPA draft with organizations and government in their countries. In July, 1982, at the UN Advisory Committee meeting the WPA was adopted. It passed the UN General Assembly later in the year.

¹³ Henry Enns, "International Disability Issues: Canadian Involvement," Winnipeg, March, 1985, p. 6, Henry Enns, Disabled Peoples' International Chairperson, Files, Winnipeg, Canada.

The WPA, accepted in 1983, was based on a different model, not the medical one. In accordance with the medical model, the professional was the expert. But, in the WPA, "disabled people are first and foremost citizens with rights, and secondly, clients of social services (paragraph 25). As citizens they have every right to benefit from the socio and economic developments in their countries."¹⁴ Thus, the philosophy of the WPA was that disabled persons as citizens with rights

have the right to participate fully in society and utilize community service[s] the same as every other citizen. Thus the World Program of Action (WPA) is based on the principles of human rights, full participation, self-determination, integration into society and equalization of opportunity, while the traditional model was based on segregation, institutionalization, and professional control (paragraph 18).¹⁵

Because the WPA was based on citizens' rights the responsibility was placed on governments for ensuring those rights. Governments were to take leadership, and provide resources to implement the WPA in their countries.

The WPA also emphasized the need for involvement of disabled people in decisions that affected their lives. Consultation must take place with organizations of disabled people. And the WPA supported the formation of such organizations.¹⁶ DPI influenced the acceptance of these principles.

DPI did not have its views incorporated in one area, that of the definitions of "disability," and "handicap." As mentioned previously, DPI rejected the WHO definitions in its revised Constitution. Disability and

¹⁴ Henry Enns, "World Program of Action Analysis," Winnipeg, ca. 1983, p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

¹⁵ Ibid., pp. 1-2.

¹⁶ United Nations, World Program of Action Concerning Disabled Persons (New York: United Nations, 1983), p. 8.

handicap were not to be defined as the fault of the disabled person. Indeed, DPI believed that handicap was a relationship between the society, its social and physical barriers, and the disabled individual. The WHO definitions were used in the WPA as there was a split in the UN Advisory Committee on which definition to accept. A compromise was reached when the WPA called on the WHO to reexamine its definitions in consultation with disabled people.¹⁷ Indeed, DPI sent representatives to WHO discussions about definitions in 1985. Most of the participants appeared satisfied with the existing definitions. But the discussions would continue on the definitions, and it was recognized that disabled people needed to take part in the discussions. Indeed, Vic Finkelstein, a DPI representative to the 1985 meeting, felt disabled people's input was important:

Able-bodied people have often enough said, quite rightly, that there should be no taxes without representation. I believe that we must say to the WHO and anyone else concerned that there should be no disability taxonomy without our representation!¹⁸

Indeed, Mauss' model of a social movement redefining the social situation, or problem, of its members applies to DPI's concern with the definition of "disability" and "handicap."

DPI greatly influenced the drafting and acceptance of the World Program of Action. Both the process of acceptance and the document itself were significant for DPI and disabled people internationally. The process proved DPI's credibility as an international voice. DPI was granted observer status at three of the Committee's meetings. DPI gained support

¹⁷ Henry Enns and Bengt Lindqvist, "Report on United Nations Advisory Committee," Winnipeg, 2p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

¹⁸ Vic Finkelstein, "World Health Organization Meeting, June 24-28, 1985, Netherlands," British Council of Organizations of Disabled People Newsletter 3 (Jan., 1986):10.

from governments for its stand, initially Canada and Sweden and then from the other Committee members. In the process, DPI gained some funding for its First World Congress, as mentioned in Chapter III. Members of the Canadian Delegation also spoke well of DPI to Canadian External Affairs and Health and Welfare. This boost helped DPI's credibility in Canada and its ability to obtain funding for its Development Program from the Canadian International Development Agency.¹⁹

Without DPI's input the WPA would not have had the emphasis it had on financial support for organizations of disabled people or on the environment being the cause of disabled people not being able to participate fully in society. International bodies and documents may not have much impact worldwide, but such documents were some of the few mechanisms for world cooperation available. Furthermore, DPI concluded that "more than a social policy document, the World Program of Action is a declaration of emancipation by Disabled People."²⁰ When the World Program was accepted in 1982, it was then up to DPI's national members to influence their governments to implement the WPA in their countries.

3. UN DECADE OF DISABLED PERSONS, 1983-1992

The UN Advisory Committee for the International Year of Disabled Persons, also sent a recommendation to the UN General Assembly to proclaim a Decade of Disabled Persons, from 1983-1992, to implement the World Program of Action. DPI saw it as its mandate to promote the implementation of WPA

¹⁹ Telephone interview with André LeBlanc, Former Director, Bureau on Rehabilitation, Health and Welfare Canada, Ottawa, Canada, June 10, 1985.

²⁰ Henry Enns, "Background to World Program of Action," Winnipeg, ca. 1984, p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

principles in the Decade. During the Decade, UN member countries were hoping to make progress in prevention, rehabilitation, and to provide resources for these activities and for organizations of disabled people. Furthermore, they were to consult with organizations of disabled people in implementing measures.

4. HUMAN RIGHTS AT THE UNITED NATIONS

DPI made representation at another international meeting, the UN Human Rights Sub-Commission. The Sub-Commission was part of ECOSOC and thus, DPI used its consultative status to make presentations. DPI's work there increased its international credibility. It also affirmed that disabled people should be protected like all other human beings. Ultimately, it made disabled people in countries around the world feel as though they were important and citizens of the world. Violations against disabled persons would no longer be hidden from public view. The Sub-Commission became a forum for disability issues where it had not been before.²¹ It brought to the Commission's attention the human rights violations of disabled people throughout the world. A Special Rapporteur, or reporter, was appointed to collect data on the human rights violations against people with disabilities in different nations.

DPI representations at the Sub-Commission began indirectly in August 1982. Disabled people in the United States had issued the report, Trust Betrayed, Hope Denied, revealing the human rights violations against disabled people that the US Reagan Administration was allowing. Reagan's cut-backs in health and social services left many disabled persons living in

²¹ Interview with Jim Donald, Chairperson, Disabled Peoples' International Human Rights Committee, Nassau, Bahamas, Sept. 18, 1985.

the community in poverty. Also, people in institutions lived in crowded, unsanitary conditions. The report was published in cooperation with DPI North America. Some disabled people and human rights attorneys in California developed the report. These people presented the report at the UN Sub-Commission meeting in August 1982. The Sub-Commission on Prevention of Discrimination and Protection of Minorities was a body of human rights experts, not representatives of countries. The Sub-Commission reported to the Human Rights Commission, which accepted or rejected resolutions for action. The Commission then reported to the ECOSOC, and the ECOSOC reported to the UN General Assembly with the findings.²²

Bruce Curtis, an American disabled activist who had been involved in the US independent living movement, made the presentation at the Sub-Commission. He recalled that throughout history disabled people were treated as less than human:

We 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 inhuman conditions. We are traditionally the last to receive the benefits or the attention of most societies.²³

He further related that disabled persons had been exterminated with Jews, gypsies and intellectuals by the Nazis in World War II. He concluded with a call for the Sub-Commission to approve a resolution regarding the rights of disabled persons. Indeed, the Sub-Commission passed a reso-

²² Henry Enns, "Report on Meeting of Human Rights Sub-Commission, Geneva, May 3-31, 1984," Winnipeg, p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

²³ Bruce Curtis, "UN Sub-Commission Presentation," August 1982, p. 1, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

lution affirming that disabled people were included under the Universal Declaration of Human Rights, even though they were not explicitly mentioned in the document. It affirmed that the Sub-Commission would promote the rights of disabled persons.²⁴

In 1983, DPI was officially represented at the Sub-Commission hearings. Two American attorneys, Jim Donald, a wheelchair user, and Karen Parker, a nondisabled person, attended the session. At this meeting, DPI provided evidence of where disabled people's rights were being violated. Indeed, the representations offered examples of the amputations and blinding practised by some nations in the Middle East and parts of Asia for crimes such as theft. They asserted that maiming or disabling the human body in any way was a violation of a person's rights.

The Sub-Commission also began to view disability as related to many different issues. Indeed, DPI presented its views on agenda items such as food scarcity, refugees and indigenous people.²⁵

By 1984, members of the Sub-Commission moved from thinking the Human Rights Sub-Commission was not the appropriate forum to air disability issues, to appointing a Special Rapporteur to look into disability and human rights violations. The Sub-Commission, in its resolution of August 29, 1984, appointed Leandro Despouy (Argentina) as Special Rapporteur. DPI endorsed him, as he had demonstrated a sensitivity to disabled people's issues and was an expert on human rights law. The Sub-Commission recom-

²⁴ Disabled People's Delegation, "Draft Resolution," to Sub-Commission on Prevention of Discrimination and Protection of Minorities, August, 1982, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

²⁵ Donald Interview.

mended that his report contain information and recommendations on:

- a. Human rights and humanitarian law violations that result in disability or have a particular impact on disabled persons;
- b. Apartheid, as it relates to disability;
- c. All forms of discrimination against disabled persons;
- d. Institutionalization and institutional abuse;
- e. Economic, social and cultural rights as they relate to disability.²⁶

The Sub-Commission also asked the Special Rapporteur to pay particular attention to the views of disabled people's organizations. The UN provided a salary for the Rapporteur, but he did not receive funds for expenses for researching a report. DPI has helped the Rapporteur to travel to various DPI meetings to meet disabled people and hear violations that have occurred in their countries.

Originally, Despouy was to report his findings in 1986. But, due to the voluminous amount of material to collect, the report was rescheduled to appear in 1988.

DPI was pleased with the job done by Despouy. He was open to consulting with organizations of disabled people. Indeed, DPI members submitted human rights violations in their countries to the Rapporteur for his report. DPI presented some of these violations at the June 1985 Sub-Commission meeting. It cited institutionalization as:

cruel, inhuman and degrading treatment. Institutionalization itself causes disabilities, in particular the institutionalized personality, which renders a person inadaptably or less adaptable to normal life in society. The phenomena [sic] of the institutionalized personality makes it difficult to diagnose and provide treatment for naturally caused disabilities--often the unnaturally caused personality is assumed to be part of the original disability. Hospitalization of disabled persons is only warranted when disabled persons need acute medical care and

²⁶ Disabled Peoples' International, "Human Rights and Disability: Report of Disabled Peoples' International to United Nations Sub-Commission on Prevention of Discrimination and Protection of Minorities, 38th Session," 1985, p. 2, in author's possession.

actually receive ameliorative acute medical care in the facility of internment.²⁷

DPI believed that no person should be institutionalized because it was like being imprisoned for life. DPI contended that independent living in the community should be encouraged everywhere. In fact, institutionalization was more of a problem in the developed world, where there was money to maintain big institutions. In the developing world, where there was little money for institutions, disabled people lived in their communities, for the most part. In addition to being institutionalized, many disabled people experienced beatings, sexual assault and were prescribed drugs to keep them passive and easier to control in an institutional setting. DPI considered such treatment torture, and inhuman and degrading treatment.

In fact, DPI presented a separate report on alleged beatings and neglect committed against mentally ill persons in several Japanese institutions. Donald, as DPI Human Rights Committee Chairperson, investigated the situation in Japan in April 1985. It was found that at one Japanese institution, with a population of 944 inmates in 1984, fifty-eight people died in 1981, seventy-nine in 1982, seventy-four in 1983, and eleven in 1984.²⁸ In addition, the fact-finding mission discovered that institutions for the mentally ill were privately-run and therefore needed to turn a profit. Thus, there was often overcrowding and drugging to control patients, since less staff were needed then. DPI noted the need for deinstitutionalization of disabled people, and Japan's negligible effort to pro-

²⁷ Ibid., p. 12.

²⁸ Etsuro Totsuka, Kantoro Nagano and Junri Ozaki, "Patient's Rights and Consumer Movement," presented at the 11th IOCU World Congress in Bangkok, Thailand, December 9-14, 1984, p. 4, in author's possession.

vide community alternatives.²⁹

Finally, DPI was concerned with humanitarian law violations that caused disabilities in the world. It cited war and armed conflict as prime disablers of people. It called for peace. It wanted nations to direct their monies away from the crippling of humankind toward instruments of life.³⁰

B. PEACE ISSUES

DPI has addressed peace issues, as they related to disability, since its founding in 1981. At its First World Congress, DPI called for 1% of all monies spent on the arms race to be redirected to useful projects that promoted life, such as clean water and food.

DPI deplored the waste of human life and the disabling effects of war. DPI declared its "Peace Statement" in Hiroshima, Japan in 1982. The DPI World Council met in June 1982 in Tokyo and drafted a "Peace Statement" before the members travelled to Hiroshima. There, they participated in a peace march through Hiroshima with people disabled in the atom bomb blast in 1945. The "Peace Statement" asserted that:

Disabled People all over the world know, from their deepest personal experience, the capacity of war to cast its mantle of death and destruction over life and limb...³¹

²⁹ Disabled Peoples' International Human Rights Committee, "Preliminary Report on the Institutionalized Mentally Ill in Japan," presented to the UN Sub-Commission on Prevention of Discrimination and Protection of Minorities, 38th Session, 1985, p. 3, in author's possession.

³⁰ DPI Human Rights Committee, "Human Rights and Disability," p. 8.

³¹ Disabled Peoples' International "Peace Statement," Hiroshima, Japan, June 24, 1982, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

It further insisted that "the 600 billion now spent a year on armaments is [sic] diverted to socially useful projects."³²

Generally, DPI's World Council members were in agreement about calling for peace. But, in Hiroshima, some World Council members drew up a peace petition that they wanted DPI to distribute worldwide; some World Council members were reluctant to circulate a petition. They claimed such a petition would not be well-received by their government or people.

DPI decided that it would embark on a "DPI Ship of Peace" project in 1986, the International Year of Peace. The Brotherhood of Man, an international sailing organization for disabled people, approached DPI with a proposal for a Ship of Peace. It would sail around the world manned totally by disabled people. It was to be DPI-sponsored and would have stopped at the UN in New York and in Hiroshima on its trip around the world. The plan was for twenty-eight disabled people to sail from Sweden in September 1986. The project was cancelled due to complications in the funding of the project. Originally, the Swedish Government and a pharmaceutical company were sponsors of the ship. However, due to conflicts between the ship's main organizer and the pharmaceutical company, the pharmaceutical funder withdrew from the project. DPI decided that the Ship was not its major priority to fund in 1986.³³ Its development program and internal operations needed funding. This ship project may yet be embarked upon in the future if funds become available.

³² Ibid.

³³ Interview with Henry Enns, DPI Chairperson, Winnipeg, Canada, July 31, 1986.

C. DPI AND THE INTERNATIONAL LABOR ORGANIZATION (ILO)

DPI was able to influence employment policies developed by the International Labor Organization (ILO). Its relationship with the ILO has increased DPI's international profile. The ILO learned that DPI existed as an organization, and that it was a credible voice of disabled people. As a result, many of DPI's views were incorporated into the ILO's Vocational Rehabilitation (Disabled Persons) Convention and Recommendation. The Convention called for the promotion of employment opportunities for disabled people in the integrated labor market. The Recommendation also set out a "series of suggested measures aimed at increasing employment opportunities for disabled persons such as assistance and financial incentives to employers to encourage them to provide training and employment for disabled persons and to make adaptation to workplaces..."³⁴

DPI again debated over definitions of disability and handicap in this process. The support of the Canadian delegation proved invaluable. DPI was placed on the ILO's Special List, a kind of consultative status, May 21, 1984.³⁵ Indeed, the ILO wished to have DPI's views on employment matters as they related to disabled people.

The issue of employment was important for everyone in society. Being a worker was a valued role, and it was associated with being an adult. Production, the direct result of work, was highly valued as well. Also, if

³⁴ Sam Niwa, ILO, "Presentation to DPI Seminar in Turku," in "DPI Seminar, Turku, Finland, August 21-24, 1983, Report," Stockholm, 1983, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

³⁵ Manuel Carrillo, Liaison Officer for Non-Governmental Organizations, ILO, to Jan Johnsson, Head of DPI Secretariat, May 21, 1984, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

people did not work, how did they adequately feed and clothe themselves and their families? Thus, employment in the mainstream of the community like everyone else was important to disabled people for self-esteem and to support themselves.

In the nineteenth century, disabled persons were beggars or laborers in workhouses. Many post-1945 sheltered workshops were similar to workhouses; they exploited disabled people's labor. Disabled people often did menial tasks, such as rolling up posters or packaging thumbtacks for \$.50 to \$1.00 US per day. This was often called vocational rehabilitation of disabled people. However, many disabled people and their organizations began to speak out against this form of employment. These workshops often did not provide training in marketable job skills to move out into the work world. Furthermore, disabled people have pushed to be integrated into the mainstream of the employment arena. The vast majority of disabled people have not worked in this workforce. In the US, in 1984, 27.4% of people with disabilities worked.³⁶ Thus, over 70% were unemployed and living on social assistance. Many unemployed disabled people lived in poverty. In addition, attitudes of society have handicapped their efforts to enter the workforce. Often, the assumption was that if persons could not walk, they could not talk, see or think either. Disabled people were seen as totally incapacitated.

³⁶ William D. Frey, "Introduction," in Economics and Equity in Employment of People with Disabilities: International Policies and Practices, eds. Rochelle V. Habeck, et al., (Michigan: University Centre for International Rehabilitation, Michigan State University, 1985), p. ix.

Employers needed education about the abilities of disabled people. They needed to be educated about "reasonable accommodation." Many work-sites were initially inaccessible to disabled people, and thus, they could not work there. For example, a wheelchair user who was a draftsman, might not be able to work at a regular drafting table because it was too high. The employer could reasonably accommodate the person at low cost by lowering the table to the person's height. Workplace modifications enabled disabled people to work like everyone else. Thus, DPI viewed the ILO Vocational Rehabilitation and Employment discussions as an opportunity to convey disabled persons' concerns about their unemployment and underemployment.

The ILO had a tripartate consultative system with workers, government and employers represented in country delegations. A convention in the ILO was binding on the governments, employers and workers who agreed to it. If a convention was to be passed, the countries belonging to the ILO would take the convention back to their countries to have government, workers, and employers ratify it. Once ratified a country was bound to implement it. And the nations had to report back to the ILO periodically on their progress in implementing the convention. A recommendation on the other hand, was more informal, as it suggested guidelines that countries could follow.

DPI worked on the ILO Vocational Rehabilitation issue with governments and other international organizations concerned with disability issues. These organizations met in Paris in April 1983 before the second ILO meeting dealing with the Vocational Rehabilitation issue. The organizations included Rehabilitation International, the International Federation

of the Blind, the International League of Societies for Persons with Mental Handicap, the World Council for the Welfare of the Blind and DPI. There, the organizations agreed that a "convention," not just a "recommendation," should be pursued at the ILO meeting in June. A convention was needed because it would be more effective in enacting changes in vocational rehabilitation, training, and employment of disabled persons.³⁷

The organizations present in Paris wanted a binding mechanism. They knew, however, that the chances of obtaining a convention at that late date were slim. Usually it took three years of sittings of the vocational rehabilitation committee. The vocational rehabilitation policy to be discussed in June 1983 was already in the form of a recommendation. And it was expected it would be accepted at this meeting.³⁸

Going into the June 1983 meeting, DPI was pushing for the participation of disabled people in vocational rehabilitation policy planning and implementation. It wanted this recognized in any ILO mechanism, just as it had insisted that the World Program of Action recognize the importance of disabled people's organizations having input on policies that affected disabled persons.

Six non-governmental organizations concerned with disability attended the Vocational Rehabilitation meeting as observers in 1983. The Canadian Government, in 1982, had recommended that disabled people be consulted and that representatives of their organizations be invited to the next meeting

³⁷ World Council for the Welfare of the Blind, "Model letter for use by national organizations of and for disabled persons to address their Governments," April 1983, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

³⁸ Ibid.

in 1983.³⁹ Some of these six organizations were disabled people's groups, such as DPI and the International Federation of the Blind. Technically, observers could speak only if they were backed by workers or employers at the meeting. In fact, DPI was almost denied the right to speak. The employers made a move to block its participation.

Indeed, controversy over the definition of disability alienated the employers from DPI. The employers were sure that disabled people would support a definition that claimed disabled persons were those who were recognized by an expert to be disabled, in other words, a professional. DPI disagreed with this definition. It contended that a disabled person defined whether he/she was disabled or not. Furthermore, DPI did not accept the WHO definition that was to be included in the policy. The US employers' representative then said the employers would not permit disabled people and their organizations to speak at the meeting. She put forth a motion at the meeting denying them speaking privileges. This caused a furor, and the workers and a number of governments were upset. This motion did not pass, because the majority wanted to hear disabled people's views on employment issues that affected them. It elevated DPI's credibility, as the issue of hearing what disabled people had to say came to the forefront. Furthermore, DPI had resources in its allies, the workers and some governments, who legitimated DPI's right to a voice at the meeting.

³⁹ Interview with Henry Enns, DPI Deputy Chairperson, Winnipeg, Canada, Sept. 5, 1985.

Three issues were debated at the meeting. The definition, as already mentioned, was hotly debated. DPI wanted the definition of disability to be a function of the relationship between the disabled person and his/her environment. This definition was not adopted. Instead, a compromise was reached whereby a disabled person meant "an individual whose prospects of securing, retaining and advancing in suitable employment are substantially reduced as a result of a duly recognized physical or mental impairment."⁴⁰ The term "duly recognized" inferred that a professional person would define whether a person was disabled or not.

The second issue that DPI pushed for was the participation of disabled persons and their organizations in vocational rehabilitation planning and implementation. DPI, again through its representatives, Henry Enns, a part of the Canadian delegation, and Ron Chandran-Dudley, DPI Chairperson, and Jan Johnsson, Head of Secretariat, lobbied the delegations for support. Ultimately, a clause calling for the participation of disabled people's organizations was included in the Recommendation.

The resulting Recommendation was a set of guidelines and principles for countries to follow, but it was not binding. The issue of whether to adopt a convention was also debated. The Swedish and Canadian workers' representatives were the prime movers. The Swedish workers introduced an amendment proposing that a convention be written and adopted supplemented with a recommendation. Ultimately, a Convention was accepted with 343 for, 0 against and 77 abstentions.⁴¹

⁴⁰ Jane Atkey and André LeBlanc, "Report on Committee on Vocational Rehabilitation Second Discussion at the ILO Conference, Geneva, June 1983," July 1983, p. 4, Disabled Peoples' International Development Office Files, Winnipeg, Canada.

Countries, then, had to take the Convention back to their nations and consult with government, workers, and employers to ratify the Convention. According to the ILO, governments must submit the new instruments to the legislative or governing body of the country, such as parliament, twelve to eighteen months after the ILO meeting where the convention was adopted. It could be defeated by this body and not ratified. Thus, organizations of disabled persons have been lobbying their governments to accept the Convention. The Convention became effective June 20, 1985. As of August, 1986, ten countries had ratified the Convention.⁴²

DPI had influence in the drafting and acceptance of the ILO Convention, and the World Program of Action Concerning Disabled Persons. It employed many resources successfully to gain international credibility. This credibility with the UN, international organizations, and some governments helped DPI influence international policies that furthered the rights of disabled people. DPI mobilized its efforts through governmental and organizational allies and through having effective leaders at international forums. Thus, by 1985 DPI had entered its "institutionalization" or peak stage, according to Mauss. In this stage a social movement becomes known in the community via the media and through lobbying the government and other public bodies. It is the point when the movement makes regular lobbying efforts with the government and becomes a credible voice on the issues the movement is concerned about. Eventually its views are included in legislative changes: "Thus, institutionalization means, for the move-

⁴¹ Ibid., p. 3.

⁴² S.I. Niwa, Chief, Vocational Rehabilitation Branch Training Dept., International Labor Organization, to Diane Driedger, Aug. 22, 1986, in author's possession.

ment, its period of greatest power, support, and fashionability....⁴³ In the institutionalization stage DPI should have the most success in having its goals and philosophies accepted by governments and international bodies and reflected in legislation and policy documents.

⁴³ Armand L. Mauss, Social Problems as Social Movements (Philadelphia: J.B. Lippincott Company, 1975), pp. 63-64.

Chapter VIII

CONCLUSION: ORGANIZATION-BUILDING

DPI was the organizational manifestation of the international multi-disability movement. While organizations such as the International Federation of the Blind and the International Federation of the Deaf represented blind and deaf people respectively, DPI spoke for people with various disabilities. Disabled Peoples' International, in its short life as an organization, has had an impact locally, nationally, regionally and internationally. Locally and nationally, the existence of DPI has spurred disabled people on to organize themselves, as they saw disabled people succeeding in other parts of the world. Mauss' social movement theory and life cycle provides an understanding of the past, present and future of DPI. First, though, DPI's success in achieving changes for disabled people will be discussed. Ultimately, DPI's greatest impact has been in inspiring disabled people to form their own organizations.

At international forums, such as the ILO and the United Nations and its bodies, DPI has had an impact on the direction of policies regarding disabled people. It is true that these policies may not have much measureable impact on the lives of disabled people at the grassroots level. But disabled people have participated in the available international forums like other groups of people in the world. People of all disabilities have had a voice internationally where there was none before.

This voice has contributed to disabled people's sense of self-esteem. At an international level, disabled people have participated in the Council, leadership training programs, and had employment with DPI. They have gained confidence that they can contribute like everyone else. But an international voice also impressed upon disabled persons that they were not alone--other disabled people felt like they did and were speaking out. Disabled persons could speak, and speak well at the United Nations. Many disabled people felt pride in this fact. Ed Roberts of the US has often said, "We are powerful and beautiful." Thus, international and national credibility helped disabled persons define who they were. They were citizens like all other human beings. They were not charity cases, clients and patients of do-gooders, social workers and doctors. They defined themselves at the United Nations, International Labor Organization and the World Health Organization meetings as being handicapped by the inaccessible environment that limited their participation.

DPI gained international credibility with the UN, ILO, and with many non-governmental development agencies, and some governments, Canada and Sweden especially. The question then is, how did such credibility benefit disabled people, if at all? Often international forums can merely be debating societies and not result in much action. DPI gained international recognition with the UN ECOSOC, ILO and UNESCO within five years of its founding. It has influenced the direction of documents--the World Program of Action, and the ILO's Vocational Rehabilitation Convention. But, realistically these documents have not meant changes for grassroots disabled people yet. The international credibility gained and the chance to voice concerns at these international forums have the potential, in the years to come, to benefit the average disabled citizen.

International bodies, governments, and international development aid agencies have begun learning about disabled people and their needs from disabled persons themselves. A new awareness of the need to include disabled people's concerns in development plans at the UN and in the programming of non-governmental agencies has dawned. The International Year of Disabled Persons, coupled with the founding of DPI, both in 1981, brought these concerns to the fore in the 1980's. This meant that more and more non-governmental organizations started to contribute funds to the administration of DPI and its Leadership Training Development Program. From 1980-85, thirteen non-governmental organizations contributed to the activities of DPI, mostly to its seminars and congresses. The UN IYDP Trust Fund and the ILO also contributed.¹ But, again, this has not resulted in overnight independence, economic self-sufficiency and improved quality of life for disabled people worldwide. There have been, however, some moves in this direction. DPI's Development Program has had a direct impact on some 400 disabled people personally. It has increased their self-esteem and skills in management, which can be used in developing disabled people's organizations and to develop employment opportunities for themselves and others.

DPI's greatest impact has been in spurring disabled people on to organize themselves. Thus, it had built its own infrastructure to include fifty-one member organizations by 1985. The development of disabled persons' groups was a by-product of some of the Leadership Training Seminars. This was the case in Guyana. After the Barbados Training Seminar in 1983, the Guyanese delegates returned to their country and founded an organization

¹ DPI, "List of Donations and Grants to DPI (Canada) Inc., 1980-85," Disabled Peoples' International Development Office Files, Winnipeg, Canada.

of disabled people. The growth of organizations, in all regions, was important for disabled people to obtain a voice and a mechanism to pressure governments on changes for disabled people. DPI has aided the credibility of some organizations, particularly in the Caribbean, where Derrick Palmer, the DPI Regional Development Officer, has met with governments, as related in Chapter V.

Finally, DPI's development has followed Mauss' social movement theory and life cycle. DPI was the international manifestation of the multi-disability movement. Thus, it was considered in this thesis as a social movement separate from other uni-disability movements, such as the International Federation of the Blind. Mauss' theories of rising expectations and relative deprivation were evident in the development of DPI. Because disabled people believed they should be partners in planning policies that affected their lives, they rejected participation in RI. They formed their own social movement to address their feelings of relative deprivation. This concept arose again when deaf people and women both expressed their frustrated expectations of equal participation in DPI. They perceived that they did not have as much power in decision-making as other groups of disabled people in DPI. In particular, the women threatened to form their own social movement in the face of their experience of relative deprivation.

Mauss' theory of consensual reality and social movements arising that redefine "social problems" relates to DPI's life cycle. In 1980 at the Rehabilitation International World Congress disabled people defined themselves as citizens with rights; they believed that they were not the patients and cases of doctors and social workers. Later, at international

forums, DPI continued to redefine the situation of disabled people. It asserted that a disabled person could not be blamed for his or her exclusion from society. Social and environmental barriers excluded disabled people.

Mauss' theory of resource management appears throughout the life of DPI. In most cases DPI successfully used its leadership, membership, strategies and tactics, philosophy and funds to foster changes for disabled people. However, conflicts in the World Council and some administrative mismanagement meant that at times resources were not used to their full potential for the movement.

Mauss' social movement life cycle provides many insights into DPI's development. The first stage of movements, according to Mauss, is "incipiency." This stage is characterized by uncoordinated, unorganized efforts for change with no established membership or leadership. The movement is a concerned public in this stage. The protest efforts of disabled people at the Rehabilitation International (RI) Congresses in 1972 and 1976 were the reactions of a concerned disabled public. They did not formally organize themselves for action at this point. Furthermore, RI tried to placate their concerns and demands for participation by establishing an ad hoc committee on participation. RI's efforts were a symptom of this stage: "Rather than generate conflict, most of the institutions and agencies of the society will attempt a restoration of the consensus through conciliation, compromise and absorption."²

² Armand L. Mauss, Social Problems as Social Movements (Philadelphia: J.B. Lippincott Company, 1975), p. 62.

The international multi-disability movement quickly moved to the "coalescence stage" when RI failed to meet disabled people's demands for equal participation right away. Disabled people at the Winnipeg Congress reacted against RI, which they perceived was oppressing them. They believed equal participation in the decision-making bodies of RI was their right. Mauss' life cycle explains that in this stage people will form ad hoc groups to formalize their demands for change. And the groups will be formed "...in response to repressive and provocative acts on the parts of the government or of other institutions of the 'establishment'; it may also occur as the result of disappointment from perceived failures of the government or society to take ameliorative action after raising general hopes and expectations that such would be forthcoming."³ RI disappointed disabled people's hopes of equal decision-making power in 1980. Thus, disabled persons formed an ad hoc Steering Committee to formalize an organization as a vehicle for its demands. Furthermore, the leadership in this stage was charismatic. The people elected to the Steering Committee were seen to possess the vision disabled people in Winnipeg wanted. Charismatic leadership continued to be influential in the next stage as well.

DPI was formed in 1981, and then moved on to the "institutionalization" or peak stage of a social movement. Mauss explains this stage:

Institutionalization in this sense is accompanied by all the characteristics of a 'full-blown' movement: society-wide organization and coordination, a large base of members and resources; an extended division of labor; regular thrusts into the political processes of the society (e.g. lobbying, campaigning in elections); and growing respectability."⁴

³ Ibid., p. 62.

⁴ Ibid., p. 63.

In this stage the movement has its greatest success through media exposure. Legislation begins to be passed to ameliorate the problems identified by the movement. The leadership can be of two types in this stage, charismatic and rational-legal. DPI retained many of its charismatic leaders from its initial Steering Committee stage. They laid the philosophical base for the organization. Rational-legal leadership was introduced into the organization as full-time staff people were employed in the DPI Secretariat and Development Office.

DPI entered the institutional stage soon after the Singapore Congress. As of its Second World Congress in 1985, it had respectability in the UN system, international development aid agencies and some governments. It influenced the "legislation" at international forums--the ILO's Convention and the UN World Program of Action Concerning Disabled Persons. Governments, UN and development aid agencies granted money for DPI activities.

In the future it will be interesting to observe what the fate of DPI, the manifestation of the international movement of disabled people, will be. According to Mauss' life cycle, the very success of a movement leads to "fragmentation" and eventual "demise." In the fragmentation stage many movement followers are lost through their cooptation into society at large. This also happens when things improve somewhat, and many of the followers feel "'things have really improved' and that the threat to their vital interests has greatly subsided."⁵ At this same stage the leaders, who remain in the movement, will fall to fighting among themselves about strategy and tactics for the future. Finally the movement will die out. This does not mean that all the problems have been solved. It is a cleaning up phase

⁵ Ibid., p. 64.

for society: "The cooptation process has appropriated the most critical elements of the movement's program, has 'bought off' many of its leaders..."⁶ Thus, the cycle of a social movement is ended. But all social movements, including DPI, leave a legacy in attitudinal and legal changes.⁷

In its institutionalization stage DPI must continue striving for its principles of self-determination, equality, integration and peace. It had all the tools at its disposal by 1985. How long DPI will be strong on the international scene and mean something to its membership will be told as the future unfolds. The struggle for rights was not over in 1985. DPI's first four years were only a beginning.

⁶ Ibid., p. 65.

⁷ Ibid., p. xviii.

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