ECONOMIC AND SOCIAL COMMISSION FOR ASIA AND THE PACIFIC

SELF-HELP ORGANIZATIONS OF DISABLED PERSONS

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A long climb...singular determination
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ECONOMIC AND SOCIAL COMMISSION FOR ASIA AND THE PACIFIC

SELF – HELP ORGANIZATIONS OF DISABLED PERSONS
Part One

GUIDELINES ON ESTABLISHING AND STRENGTHENING SELF-HELP ORGANIZATIONS OF DISABLED PERSONS

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PREFACE

In the course of the United Nations Decade of Disabled Persons (1983-1992), it has come to be increasingly recognized that the majority of people with disabilities, particularly those in developing countries, continue to be marginalized from mainstream development policies and programmes. According to United Nations estimates, no more than 2-3 per cent of the disabled people who need rehabilitation are receiving such services. Lack of participation and self-representation of people with disabilities in processes that determine policies and services affecting their well-being has contributed to the neglect of their needs.

As part of its effort to address these concerns, the Economic and Social Commission for Asia and the Pacific (ESCAP) undertook a project entitled "Assistance to the development of self-help organizations of disabled persons". The preparation of Self-help Organizations of Disabled Persons is an activity under the project.

The publication has been prepared to promote and support the self-help movement of people with disabilities in Asia and the Pacific. It is hoped that through such self-help initiatives to establish independent and productive lives as are outlined in this publication, people with disabilities may contribute directly to the fulfilment of the goals of full participation and equality in social life and development. These goal are contained in the World Programme of Action concerning Disabled Persons, adopted by the General
Assembly on 3 December 1982, by resolution 37/52.

It is further hoped that the issuance of this publication on the threshold of 1992—the year that concludes the United Nations Decade of Disabled Persons—will provide a special impetus to all Governments, organizations and individuals who are concerned with disability issues to commit themselves to supporting organizations of people with disabilities.

In the preparation of this publication, the ESCAP secretariat consulted numerous experts. It convened in February 1991 the Expert Group Meeting on Self-help Organizations of Disabled Persons to seek comments on a preliminary draft that it had prepared. Case-studies of organizations of disabled persons presented at the Meeting are contained in Part two of this publication. The draft guidelines on establishing and strengthening self-help organizations of disabled persons were field-tested at an ESCAP-supported national training workshop held at Kathmandu in July-August 1991. The ESCAP secretariat also circulated the guidelines in draft form to a number of experts for review and comment.

Appreciation is expressed to all those experts, among whom are outstanding leaders of organizations of disabled persons in the ESCAP region. Special thanks are expressed to Disabled Peoples' International (DPI)-Australia, and in particular to the Disability Resources Centre, Victoria Branch of DPI-Australia, which provided the secretariat with a
number of ideas and materials used in the preparation of the guidelines. For comments that were valuable in enhancing the guidelines, thanks are also expressed to Mr. Suresh Ahuja, Chairman, Committee on Social Development, World Blind Union, and Mr. Ron Chandran-Dudley, President, Disabled People's Association, Singapore.

This publication was made possible through the generous financial assistance of the Government of Japan.
Part One

Guidelines on Establishing and Strengthening Self-help Organizations of Disabled Persons
I. BACKGROUND


The main objectives of the World Programme of Action are to promote effective measures for the prevention of disability, rehabilitation and realization of the goals of full participation and equality for persons with disabilities.

The World Programme of Action stresses that for its implementation at the national level, it is necessary for Member States to, *inter alia,*¹:

Support the establishment and growth of organizations of disabled persons;

Facilitate the participation of disabled persons and their organizations in decisions related to the World Programme of Action.

¹ United Nations, *World Programme of Action concerning Disabled Persons,* (New York, 1983), para. 90 (f) and (k).
In 1987, ESCAP convened a regional expert seminar at Bangkok to review achievements at the mid-point of the Decade in the Asian and Pacific region. The seminar reported that while some progress had been made with regard to the prevention of disability and rehabilitation, relatively little had been achieved concerning equalization of opportunities for disabled persons.

In many countries and areas in the region, the development of disabled persons’ organizations is at a nascent stage, and their management and operation tend to be weak. Many lack organizational know-how and resources. In spite of the adoption of United Nations resolutions in the course of the Decade urging action to be taken in favour of the full participation of disabled persons at all levels of society, there is a lack of involvement of disabled people and their organizations in policy planning and programming in those areas which directly concern them and their families.

The 1987 seminar called upon the ESCAP secretariat, ESCAP members and associate members and other concerned agencies and organizations in the Asian and Pacific region to provide assistance in establishing and strengthening self-help organizations of disabled persons in order to enhance the participation of disabled persons at all levels of society.

In 1988, the General Assembly, through its resolution 43/98, requested the Secretary-General to, *inter alia*, promote and support the establishment of strong national organizations of disabled persons.

In an effort to address those concerns, the ESCAP secretariat undertook the implementation of a regional project entitled "Assistance to the development of self-help organizations of disabled persons". The overall objective of the project is to promote the equalization of opportunities of disabled persons through strengthening their self-representation at all levels as a means of ensuring their full participation and integration in society. The preparation of guidelines on establishing and strengthening self-help organizations of disabled persons and the conduct of training workshops are among the activities of the project.

The guidelines are primarily intended for use by groups of disabled persons that aspire to organize themselves in order to articulate their own needs and seek equal opportunities for participation in community life.

It is recognized that large numbers of disabled persons in Asia and the Pacific have been deprived of educational and training opportunities, of both a formal and a non-formal nature. In this situation, the assistance of facilitators and animators would be valuable in communicating to those disabled persons the contents of the guidelines and in supporting their initiatives to develop their own organizations.
People who could serve as facilitators and animators in the establishment and strengthening of self-help organizations of disabled persons, especially in the initial stages, include middle-level community-based rehabilitation fieldworkers, leaders of women's groups, parents of children and young people with disabilities, community health action personnel, agricultural extension, and youth development workers, and schoolteachers. The guidelines are also directed at such people.

While every attempt has been made to enhance the relevance of the guidelines to the societies of the Asian and Pacific region, the user should give due consideration to the specific social, cultural, economic and political contexts in which a self-help organization of disabled persons is to be established and strengthened.
PEOPLE
WORKING TOGETHER
FOR A
BETTER FUTURE

OVERCOMING PROBLEMS

- SUITABLE HOUSING
- LACK OF RESOURCES
- PUBLIC AWARENESS
- SOCIAL INTEGRATION
- PUBLIC ACCESS

IF YOU HAVE A DISABILITY, OR IF YOU KNOW, OR ARE RELATED TO ANYONE WHO HAS, YOU SHOULD BE INTERESTED IN THE P.D.P.A. CALL ON 31 1203 OR 355 WALMANU ROAD, SUVA

Poster of a self-help organization
Of people with disabilities
II. HOW TO USE THE GUIDELINES

The guidelines are contained in seven sections. Key terms used are defined in the following section, which provides a common basis for understanding.

Section IV “Why begin?” and section V “How to begin” deal with the "establishment" part of the guidelines. Section IV clarifies some of the reasons why disabled people may wish to set up self-help organizations. Section V leads the beginner through a simple step-by-step introduction to setting up an organization.

If an organization has existed for some time, the user may proceed directly to section VI.

Section VI, "How to strengthen self-help organizations", consists of two parts that deal with guiding principles and strategies respectively. The principles are elaborated in strategies, of which there are 15 altogether. They are not in chronological order and the user need not adhere to the order in which they appear in this publication, but may focus on those strategies which are most relevant to her or his needs.

Section VII contains suggestions regarding dissemination of the guidelines.
III. DEFINITIONS

A. Disability and handicap

The words "impairment", "disability", and "handicap" are sometimes used interchangeably. The distinction between "disability" and "handicap" has become a major philosophical point for the disability movement which focuses on breaking barriers, both physical and attitudinal, to the participation of disabled people in society.

Disabled Peoples' International (DPI)-Australia defines disability as follows:

Disability is a functional limitation within the individual caused by physical, intellectual, emotional, or sensory impairments.3

The World Programme of Action concerning Disabled Persons defines handicap as follows:

Handicap is ... a function of the relationship between disabled persons and their environment. It occurs when they encounter cultural, physical or social barriers which prevent their access to the various systems of society that are available to other citizens. Thus,

handicap is the loss or limitation of opportunities to take part in the life of the community on an equal level with others.\textsuperscript{4}

To strengthen this view of "handicap" as a function of the relationship between disabled persons and their environment, the Canadian Society for the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and the Quebec Committee on ICIDH argue that:

Handicap is the \textit{situational result} of an interactive process between two sets of causes:

- The characteristics of a person's impairments and disabilities resulting from \textit{diseases or trauma};

- The characteristics of the environment that create \textit{social or environmental obstacles} in a given situation.

In concrete terms, this view means that, depending on the environmental obstacles they face, persons with an impairment or disability may or may not experience a situation creating a handicap. It is no longer appropriate, then, to refer to the 'permanent status' of a person with a disability. It is more appropriate to

speak of a person experiencing one or more situations creating a handicap.  

From the perspective of vocational rehabilitation and employment of disabled persons, the International Labour Organisation (ILO) defines a disabled person as "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".  

B. Self-help

The potential for self-help exists in every individual irrespective of disability. The ways in which a person with a disability may express this potential depends on the extent to which she or he realizes that she or he is an agent of change, and a solver of problems, not a problem per se. 

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6 ILO Recommendation 168, section I. para.1.

Self-help requires self-motivation, i.e. the individual's motivation to improve herself or himself and situations that impinge on her or his well-being, as a prerequisite to the achievement of full participation in society. This means that the individual must have some choice in determining the direction of her or his life.

The self-help concept, especially when used in terms of the disability movement, has often been misunderstood as implying seclusion or segregation from the community. On the contrary, self-help means mutual support and empathetic human relationships. It is group solidarity which enables disabled people who are experiencing similar hardship to support each other and to overcome common difficulties through the exchange of practical information, insight and knowledge gained through personal experience. That solidarity and mutual support serves as a basis for collective action to improve the existing situation of people with disabilities in society.

C. A self-help organization of disabled persons

A self-help organization of disabled persons is an organization run by self-motivated disabled persons to enable

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8 Ibid.

Mutual support: a basis for self-help

disabled peers in their community to become similarly self-motivated, and self-reliant. The organization may engage in efforts to provide community-based support services (see the next definition) through mutual support mechanisms and advocacy for disabled persons to achieve their maximum potential, and assume responsibility for their own lives.

Thus, a self-help organization of disabled persons may be characterized by self-determination and control by disabled persons, self-advocacy and mutual support mechanisms, aimed at strengthening the participation of people with disabilities in community life.
D. Support services

Support services enable disabled persons to live as equal members of the wider community. These services include peer counselling (counselling by and for disabled persons), information and referral services on community resources (public and private) that disabled persons may avail themselves of, social skills training for disabled persons to learn to make their own decisions in day-to-day living, advocacy for disabled individuals to obtain the services and equipment needed, community-level advocacy for the integration of disabled persons in the community, and other services which are deemed necessary, depending on the needs of disabled persons in a particular community.

E. Independent living

To disabled persons who are familiar with the achievements of the disabled movement, especially during the United Nations Decade of Disabled Persons, independent living means:

“living just like everyone else---having opportunities to make decisions that affect one’s life, being able to pursue activities of one’s own choosing---limited only in the same ways that one’s non-disabled neighbours are limited.

Independent living should not be defined in terms of living on one’s own.... Independent living has to do with self-determination. It is having the right and the opportunity to pursue a course of action. And, it is