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SOCIAL DEVELOPMENT: QUESTIONS RELATING TO THE WORLD SOCIAL SITUATION AND TO YOUTH, AGEING, DISABLED PERSONS AND THE FAMILY

Letter dated 6 November 1991 from the Permanent Representative of the Philippines to the United Nations addressed to the Secretary-General

I would appreciate it if you could circulate as an official document under agenda item 94 (a) the attached annexes entitled:

I. Guidelines for the establishment and development of national coordinating committees on disability;

II. Guidelines for the development of organization of persons with disabilities.

(*Signed*) Sedfrey A. ORDOÑEZ
Ambassador
Permanent Representative

Annex I

GUIDELINES FOR THE ESTABLISHMENT AND DEVELOPMENT OF NATIONAL COORDINATING COMMITTEES ON DISABILITY

A. TOWARDS A SOCIETY FOR ALL - THE ROLES AND FUNCTIONS OF NATIONAL COORDINATING COMMITTEES ON DISABILITY IN PLANNING AND DEVELOPMENT

1. We, the government representatives from developing and developed countries, engaged in a fruitful debate and dialogue during the International Meeting on the Roles and Functions of National Coordinating Committees on Disability in Developing Countries, held at Beijing from 5 to 11 November 1990, have decided to place on record our collective analyses, conclusions, policy recommendations and action proposals for consideration by the international community, with a view to reaching the objective of "A Society for All" in a world of equal opportunity and common sharing of material and cultural values.

2. Throughout the Meeting, the spirit and philosophy enunciated in the World Programme of Action concerning Disabled Persons and the objectives of the United Nations Decade of Disabled Persons (1983-1992) a/ have guided our thinking.

3. We affirm that the World Programme of Action is a reflection of a major change in social thinking and an important expression of a new social design, the fundamental philosophy of which is based on the right of every human being to equal opportunity and freedom. The Programme reflects a redirection of thinking on disability issues: from a one-sided, purely medical or charitable approach, towards one of enablement and empowerment. It has opened the way to a future in which people with disabilities may participate in society as citizens with full rights and responsibilities. It should, therefore, remain a valuable guide for action in the 1990s and beyond. We fully associate ourselves with the fundamental goals set out in the World Programme of Action in promoting global activities on behalf of disabled people and, in particular, in increasing public awareness of disability issues.

4. We appreciate the positive contribution of the United Nations Decade of Disabled Persons, with its underlying principle of equality and participation. We are also united in our conviction that the opportunities offered by the Decade to stimulate global implementation of the World Programme of Action have neither been fully explored nor exploited. In most countries, the issue of disability has been given low priority, while the momentum generated by the International Year of Disabled Persons (1981) has not been maintained. Political will and unremitted long-term efforts are still needed to achieve the goals of full participation.

5. We recognize that the realization of the goals of the World Programme of Action is closely related to the political, social and economic development of

each country. It is evident, therefore, that the problems of disabled persons cannot be viewed and resolved in isolation. In tackling disability issues, it is essential that action should not only be closely linked to the economic and social development in a specific country. It should also take into consideration the various historical and cultural backgrounds, with their positive characteristics.

6. In order to effectively address disability issues, it is essential that action should be closely linked with the existing networks of health care, education and employment. Mass media should be fully utilized in mobilizing public opinion, and effectively involving it in disability issues. Governments should play a leading role in increasing resources, enacting and improving disability legislation, facilitating access to knowledge, information and upgrading of skills, in order to develop talents and potentials. These elements should be incorporated into national development planning and programming.

7. We note with deep concern that the very survival of some developing countries is threatened by a deterioration of their economic and social situation as reflected in the standards of living, and by the growing numbers of people living in extreme poverty. The gap between the economic status of developed and developing nations is widening. The economy of developing countries has further deteriorated, resulting in even greater challenges in realizing disability programmes.

8. It is estimated that there are over 500 million disabled people in the world, with some 80 per cent of them living in developing countries. The principles and objectives of the World Programme of Action should be realized by focusing more efforts on disability issues in developing countries. Practical measures should be taken to provide necessary assistance to promote their socio-economic development, thereby changing effectively the status of disabled persons.

9. It should be recalled at the same time that the World Programme of Action is designed for all nations. However, the time-span for its implementation and the priorities to be implemented vary among nations. This will depend on the availability of their resources, levels of socio-economic development, cultural factors, and the nations' capacity to formulate and implement action envisaged in the Programme.

10. We strongly believe that at the international and regional levels technical assistance and technical cooperation are valuable assets in achieving the goals of the Decade. More efficient coordination is needed in order to obtain maximum benefits from available resources. We call upon all countries and international organizations concerned to consider seriously the needs of disabled people and include them in bilateral and multilateral development cooperation programmes.

11. We recommend that the period following the United Nations Decade of Disabled Persons be one of action for and with disabled persons, with a view to turning the ideals of full participation and equality into reality, creating "A Society for All" by the year 2010.

12. In view of the complex, multidisciplinary nature of disability issues, which transcends artificial boundaries, we strongly urge Governments to establish an organizational framework - or strengthen the existing one - as a permanent structure. This would enable full and effective coordination of efforts at the national level and constant monitoring of progress in achieving the goals of the national plan.

13. The concept of equal opportunity cannot be successfully translated into action without the close collaboration and direct involvement of all policy- and decision-makers, relevant government departments, employers, trade unions, municipalities, professionals, the disabled persons themselves and their organizations.

14. We take note of the outcome of the first review of the implementation of the World Programme of Action concerning Disabled Persons (Stockholm, August 1987) and of the Meeting on Alternative Ways to Mark the End of the Decade (Järvenpää, Finland, May 1990). These meetings have identified the lack of national coordinating mechanisms in many countries as the major obstacle to the implementation of the World Programme of Action and the achievement of the objectives of the Decade. Such mechanisms require a stronger and clearer mandate from respective Governments and should play a key role in the preparation or updating of the national plans and in monitoring their implementation.

15. We therefore recommend that the General Assembly approve these "Guidelines for the establishment and development of national coordinating committees on disability", to provide standards and encouragement for all members of the international community.

B. PRINCIPLES FOR THE ESTABLISHMENT AND DEVELOPMENT OF NATIONAL COORDINATING COMMITTEES ON DISABILITY

1. Introduction

16. The World Programme of Action concerning Disabled Persons recognizes the need to "establish a focal point, e.g. a national commission, committee or similar body, to look into and follow the activities related to the World Programme of Action of various ministries of other government agencies and of non-governmental organizations. Any mechanism set up should involve all parties concerned, including organizations of disabled persons. The body should have access to decision makers at the highest level".

17. Disability covers a complex, multidisciplinary field of work, with major integrated themes such as prevention, rehabilitation, social integration and equality of opportunities, including opportunities for full participation by disabled persons themselves. A collaborative partnership is called for in approaching questions of disability involving, at the national level, several ministries and other bodies within the public, private and voluntary sectors, along with disabled persons' organizations. This can best be pursued through the establishment of a permanent structure that allows effective coordination of national efforts. At the international level, they are dealt with by the United Nations specialized agencies, and by various intergovernmental and non-governmental organizations.

2. Statement of purpose

18. The purpose of a national coordinating committee is:

(a) To promote the full integration, independence and productivity of persons with disabilities in the community, school, the workplace and all other aspects of society;

(b) To provide equal opportunities for disabled persons, meaning the process through which the general system of society is made accessible to all, such as the physical and cultural environment, housing and transportation, social and health services, education, work opportunities, cultural and social life, including sports and recreational activities.

3. Developing disability policies through a multisectoral and multidisciplinary strategy

19. The World Programme of Action stipulates that Member States should initiate national long-term programmes to achieve their objectives. Such programmes should be an integral component of a country's general policy for socio-economic development. It also recommends that matters concerning disabled persons should be treated within the general context of a comprehensive, rather than a selective approach.

20. Realization of the objectives of the World Programme of Action will require a multisectoral and multidisciplinary strategy for combined, coordinated policies and actions relevant to the provision of equal opportunities for disabled persons as well as effective rehabilitation services and measures for prevention.

21. Policies to be designed will vary from country to country, depending on requirements, the level of socio-economic development attained, cultural traditions and available resources. Disabled persons, through their organizations, should have substantial influence in designing such policies, programmes and services aimed at benefiting them. Disabled persons should make their views known, and make significant contributions to the planning

process. Their active involvement in national coordinating committees is therefore crucial for the success of the committees.

22. Translating the important concept of equality of opportunity into action means opening up all sectors of society to disabled persons (health, education, employment, culture, sport, etc.). Acceptance of this concept implies a willingness to formulate an overall policy concerning disabled persons, and taking on an intersectoral approach to coordination.

23. If coordinated policies and programmes concerning prevention, rehabilitation and equalization of opportunities, instilled by a well-established committee, are lacking, a comprehensive overview of the situation will be hard to obtain in the short term. A national committee should be considered the focal point for collaborative and coordinating ventures and contacts. For satisfactory programme coordination, where no such body exists, time-consuming discussions will have to be held with representatives of all relevant government ministries convening planning, health, social affairs, education, culture, employment, housing, transportation and communications, and with non-governmental organizations.

24. The Manual on the Equalization of Opportunities for Disabled Persons b/ states that "In order to develop a coherent policy concerning disabled persons, it will be necessary to form new or strengthen existing national committees responsible for disability matters. The role of such committees should be to encourage development and initiatives at the grass-roots level, as well as at the national and regional levels and to help pooling of information and resources. However, over-coordination of activities could have a stifling rather than a stimulating effect. To break new ground in meeting the needs of disabled persons, a variety of ideas and solutions is needed."

25. Each ministry or body within the public or private sector should include disabled people within their specific areas of responsibility in the same manner as non-disabled people. Services for disabled persons should, whenever possible, be available within the existing social health, education and labour structures of society. Existing schools, health and social services should be modified or strengthened where necessary in order to provide for the needs of disabled persons.

4. Special considerations for disabled persons in developing countries

26. In view of the fact that as many as 80 per cent of all disabled persons live in developing countries, and that approximately 50 per cent of these countries' populations, including families and relatives, could be directly or indirectly adversely affected by disability, there is a need for Governments to grant high priority to establishing or strengthening national coordinating committees or similar bodies. Most essential in the developing countries are the preparatory activities and the groundwork required (such as awareness

campaigns, leadership and management training), taking into account the specific conditions of the country, its resources, the time span of programme implementation, and the choice of items to be implemented.

5. Definition, goals and functions of a national coordinating committee

Definition

27. A national coordinating committee in the field of disability:

(a) Is an autonomous body established by Government through legislative measures, administrative or other legal procedures to review, coordinate and advise on the activities of all agencies and non-governmental organizations working for and on behalf of people with disabilities;

(b) Acts in a professional advisory capacity in relation to government and policy makers on all issues affecting the well-being of people with disabilities, including children and women;

(c) Serves as a national focal point on disability matters to facilitate the continuous evolution of a comprehensive national approach to the prevention of disability, rehabilitation and equalization of opportunities;

(d) Includes representation from concerned government agencies, eminent persons committed to disability issues and non-governmental organizations, with special emphasis on adequate representation from organisations of people with disabilities.

Goals

28. The goals of the national coordinating committee are as follows:

(a) To promote and encourage the development of policy recommendations including policy coordination, planning, monitoring of programmes, information, utilization and dissemination, research and training;

(b) To review and evaluate on a continuous basis the effectiveness of all existing policies, programmes and activities concerning disabled people;

(c) To play a key role in the preparation of a comprehensive national plan and in the development of national policy and legislation on disability and related issues, which will serve as the basis for a network of services that can benefit all disabled people within their communities;

(d) To encourage an international exchange of experience and state-of-the-art technology; and to help to elucidate how bilateral and multilateral cooperation can improve the living conditions of disabled persons, particularly in developing countries;

(e) To encourage the creation and strengthening of organisations of disabled persons;

(f) To promote the participation of disabled persons in all forms of activities and to strive to remove inequalities that exist between them and other citizens;

(g) To help devise a systematic procedure for understanding the needs of disabled persons, in both urban and rural areas;

(h) To maximise efforts in the promotion of the World Programme of Action and to inspire effective measures, based on the provisions and priorities set forth in the national plan, for the prevention of disability, for rehabilitation and for the realisation of the goals of "full participation" of disabled persons in social life and development, as well as those of "equality";

(i) To serve as a resource centre for documentation, materials and technical support.

Functions

29. The major functions of the national coordinating committee are as follows:

(a) To work, realising that national Governments bear the ultimate responsibility for the implementation of national action, to ensure that both local authorities and other bodies within the public and private sectors are called upon to implement the national measures contained in the World Programme of Action;

(b) To work, where ongoing national social policies exist, to expand and extend these policies directed at improvement of the status of disabled persons and support of their families;

(c) To establish procedures to monitor, on a constant basis, implementation by all relevant agencies and to draw attention to the need at the national level to coordinate policies and programmes for disabled persons;

(d) To emphasize, in recognition of the fact that large numbers of disabled persons continue to be victims of war and other forms of violence, the need for national and international peace as well as respect for human rights;

(e) To be actively involved in the process of revision of terminology on impairment/disability/handicap;

(f) To plan, promote and help in the dissemination of information and the creation of greater awareness through all types of media, including traditional and cultural forms of communication, in order to ensure a positive but realistic portrayal of disabled persons and disability;

(g) To strive to link the programmes for and the solution of problems of disabled persons with overall socio-economic development at the national level;

(h) To organize local or national seminars, workshops or meetings on special themes of disability in order to educate people regarding these themes, to promote awareness of the problems and to find suitable solutions within the national context;

(i) To report annually to the head of State and/or to the parliament or any other appropriate high-level body;

(j) To extend its areas of interest to cover legal rights, medical and/or social rehabilitation, prevention and early diagnosis/health and welfare services, education and vocational training, counselling and guidance, employment quotas and subsidies, research and documentation, training of professionals and informal careers, and the application of technology and science to help solve problems relating to disability;

(k) To promote, at the national level, an information base on services, organizations, institutions, programmes and activities related to disabled persons and disability issues.

6. Organizational structure

30. Any national coordinating machinery should be so structured as to reflect the intersectoral and multidisciplinary nature of issues of disability and to provide for the necessary intersectoral consultation, coordination and implementation. National priorities and resource constraints should be duly taken into account.

Location

31. To enable the national coordinating committee to communicate and operate with central decision-making authorities, the national committee body should be located close to the centre of power and have the capacity to influence the coordination of planning and ongoing activities and to identify areas where attention is required. Attachment to the office of the head of State, Government or the parliament is the most effective.

32. If it is deemed necessary to attach the committee to a single ministry, arrangements should be made to ensure the full participation in decision-making of representatives from other ministries and to guarantee the committee's access to information about the work of all relevant agencies of the Government.

33. The national coordinating committee should be institutionalized as a permanent body, in order to meet the challenges of its tasks. To be effective, it should be based on legal and other appropriate administrative

regulations and have permanent infrastructural support. It may also have its counterpart at the regional and local levels.

Size and composition

34. The number of members on a national coordinating committee will vary from one country to another. The size of the committee, however, should be such as to enable it to achieve its objectives with efficiency. Its membership, therefore, should be limited to a workable size, with specific terms of reference. Outside experts may serve on working groups on specific issues.

35. A mixture of private and public sector membership is most desirable for the functioning of the committee, as it gives an intersectoral and multidisciplinary composition. Where a national committee already exists, it should be reinforced at the highest level in order to reach out to the grass roots.

36. The national coordinating committee should be composed of:

(a) Representatives of all concerned government ministries;

(b) Representatives of organizations of disabled persons, taking into account the different categories of disabilities;

(c) Representatives of non-governmental organizations;

(d) Rehabilitation professionals;

(e) Persons with expert knowledge of, or with special concern for disability issues, including representatives of mass media.

37. Representatives of international organizations or local offices of United Nations agencies and bodies may be invited to serve as observers on the committee.

Chairperson

38. The Chairperson of the national coordinating committee should preferably be a disabled person of high status in the community. This person should possess a commitment to disability issues, leadership capabilities and have easy access to the public and private sectors of society, especially at the highest level of decision-making.

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7. Linkages at the national level

Decision-making authorities

39. Linkages with decision makers is in conformity with the catalytic role of the national coordinating committee, which should influence and persuade them to integrate disabled persons' concerns into national planning. Structural relationships should therefore exist between the national coordinating committee and policy makers in a given country, and ways must be found of forging such links. One way may be to involve high-level decision makers in the committee itself. Governments should give due consideration to proposals made by the national coordinating committee on disability issues and include them in the United Nations Development Programme (UNDP) country programme and national plans.

Mass media and organizations at the grass-roots level

40. In order to enable the national coordinating committee to influence positively the attitude of the public towards disabled persons, linkages with the mass media networks should be made through all possible social, labour, political institutions, the private sector and non-governmental organizations.

Research institutes

41. Linkages with research and survey offices should enable the national coordinating committee to collect, analyse and disseminate information on trends pertaining to the conditions of disabled persons.

8. Linkages at the regional and subregional levels

42. Linkages should be developed at the regional and subregional levels between national coordinating mechanisms. The United Nations regional commissions have an important role to play in this respect by organizing, first, exchanges between various national committees within the region, and secondly, on an interregional basis.

9. Linkages at the global level

43. National coordinating committees should endeavour to establish effective working relations with the Commission for Social Development, the Economic and Social Council and the General Assembly. They should also seek to establish links with international organizations. To this end, the capacity of the committees to deal with such organizations should be strengthened. Training in monitoring and evaluation methods should, therefore, be offered globally to national coordinating committees.

10. Operations of a national coordinating committee

Basic premises

44. A national coordinating committee should meet regularly to ensure continuity of its work.

45. A national coordinating committee should have at its disposal basic resources (to be provided by the Government), such as its own budget, office space and support staff to facilitate its ongoing work and to provide continuity.

46. A national coordinating committee should consider establishing one or more subcommittees or working groups to facilitate its work. These may be established on the basis of issues related to education, employment or independent living, and/or on the basis of types of disability (e.g., visual and hearing impairments, mental impairments and other physical disabilities).

47. A national coordinating committee may wish to operate in conjunction with a network of local councils or committees acting as contact points. In this event, the national committee must ensure the effective flow of communications with its contact points regarding objectives and needs.

48. The national coordinating committee may wish to promote an annual theme or slogan to highlight its main goals or activities.

11. Management issues

49. The management issue is complex in view of the cross-sectoral and multidisciplinary nature of disability. Nevertheless, good management of a national coordinating committee is of crucial importance as its quality determines the efficiency and effectiveness of the committee. The professionalism and competence of the managerial staff should therefore be constantly upgraded and improved.

50. The national coordinating committee should be managed and operated by professional staff and preference should be given to disabled persons.

51. It is a prerequisite in this case that disabled persons should be offered opportunities to be trained in management techniques and procedures in order to qualify for work within the national coordinating committee.

12. Funding

52. The national coordinating committee must have funding, allocated for basic operating costs, public relations and promotional activities. The national coordinating committee should help to identify internal and external sources of funding for disability-related projects and programmes.

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C. TECHNICAL COOPERATION IN THE FIELD OF DISABILITY: THE ROLE OF NATIONAL COORDINATING COMMITTEES

1. Introduction

53. Until recently, the social dimension of development in general, and disability issues in particular, have not been accorded high priority in technical cooperation activities. During the Decade, relatively more progress has been made concerning prevention and rehabilitation.

54. The Vienna Affirmative Action Plan, c/ formulated by the World Symposium of Experts on Technical Cooperation among Developing Countries and Technical Assistance in Disability Prevention and Rehabilitation, underlines the importance of promoting equal opportunities in technical cooperation.

55. It is recognized that national coordinating committees have a critical role to play in the development of national disability policies and programmes. However, the potential of national coordinating committees, both as instruments and targets of technical cooperation, has not been fully explored.

56. To further implement the World Programme of Action concerning Disabled Persons, the role of national coordinating committees in technical cooperation should be guided by three main strategic approaches:

(a) All development programmes should consider disability issues as an integral part of overall development efforts;

(b) Programmes specifically designed to improve the status of disabled persons should be promoted;

(c) Organizations of people with disabilities should be fully involved at the appropriate level in planning, implementation, monitoring and evaluation of technical cooperation activities concerned with disability.

57. Promotion of national disability policies and programmes may encounter long-term difficulties unless there is strong national commitment to social development. Technical cooperation should be an important mechanism facilitating this process. Disability issues should be incorporated into comprehensive national social policy plans. A useful framework for such plans is contained in the "Guiding Principles for Developmental Social Welfare Policies and Programmes", d/ endorsed by the General Assembly in its resolution 42/125 of 7 December 1987.

2. Goals of technical cooperation in the field of disability

58. The goals of technical cooperation in the field of disability, with which national coordinating committees should be concerned, are the following:

(a) Integration of the needs, rights and concerns of people with disabilities in development planning and projects;

(b) Strengthening of expertise for the effective functioning of national coordinating committees;

(c) Enhancement of the development and strengthening of comprehensive national disability policies and programmes;

(d) Support of the development of organisations of disabled persons so that they can contribute effectively to the work of national coordinating committees.

3. Areas for technical cooperation in support of the establishment and strengthening of national coordinating committees

59. Within the framework of the Vienna Affirmative Action Plan and the World Programme of Action, international assistance from both bilateral and multilateral sources should be provided for the establishment and development of national coordinating committees.

60. Technical cooperation in this context should focus on:

(a) Formation of national coordinating committees with emphasis on identification and mobilization of prospective members and supporters of national coordinating committees; material and financial resources; and information;

(b) Development of self-help organizations of people with disabilities to undertake advocacy of the needs and potentials of disabled persons in national coordinating committees;

(c) Management of national coordinating committees;

(d) Assistance in acquiring training materials and other facilities for strengthening the committees, particularly in the analysis of policy issues, policy formulation, programme development, as well as the monitoring and evaluation of project implementation;

(e) Provision of training opportunities, technical advice and equipment, as well as information in accessible formats to ensure the accessibility of committee meetings and the effective participation of disabled persons in committee activities.

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4. Role of national coordinating committees in technical cooperation

61. Within the framework of technical cooperation, national coordinating committees could be engaged in the following activities:

(a) Increase of public awareness through campaigns directed at the general public, governmental agencies, non-governmental organizations and people with disabilities;

(b) Examination of ongoing programmes and projects, with a view to strengthening disability components in those programmes and projects, and channelling of the results to potential cooperation partners;

(c) Identification of new programme and project possibilities for technical cooperation and dissemination of this information to planning and executing agencies;

(d) Planning and, if applicable in the national context, implementation of programmes and projects, in cooperation with implementing agencies;

(e) Examination of the extent to which development programmes and projects meet the goals of the World Programme of Action and other related internationally established guidelines.

5. Linkages between national coordinating committees and donor agencies and international organizations in technical cooperation

62. Those agencies in donor countries responsible for planning and undertaking technical cooperation activities should develop consultative mechanisms with national coordinating committees of recipient countries to review their funding policies and examine the benefits to disabled persons.

63. The international organizations of disabled people are essential sources of expertise and information for planning and implementing technical cooperation activities to benefit disabled persons. United Nations agencies, donor agencies and international organizations are urged to consult the organizations of disabled people.

64. The role of the focal point on disability in the Centre for Social Development and Humanitarian Affairs of the Secretariat should be strengthened through the following measures:

(a) The establishment and updating of an information network, including a directory of experts on disability, to facilitate the sharing of information and experience among national coordinating committees and other agencies needing such assistance;

(b) Regular reviews of technical cooperation activities undertaken by various United Nations agencies and international organisations through inter-agency consultative mechanisms.

65. The United Nations, its specialised agencies and particularly the regional commissions, should facilitate the exchange of expertise among national coordinating committees in the developing countries.

D. STRATEGIES FOR IMPLEMENTATION

66. Governments should adapt these Guidelines to their own national requirements and develop objective strategies that are applicable to their individual situations.

67. They should organise national meetings in order to create a common understanding of what national committees are.

Notes

a/ A/37/351/Add.1 and Corr.1, annex, sect. VIII, recommendation I (IV).

b/ ST/ESA/177, chap. III, para. 2.

c/ IYDP/SYMP/L.2/Rev.1 of 16 March 1982.

d/ See E/CONF.80/10, chap. III.

Annex II

GUIDELINES FOR THE DEVELOPMENT OF ORGANIZATIONS OF DISABLED PERSONS

PREFACE

These guidelines have been prepared as part of an innovative activity to realize one of the objectives of the World Programme of Action concerning Disabled Persons, adopted by the General Assembly in its resolution 37/52 of 3 December 1982. It is stipulated in the Programme that:

> "Every effort should be made to encourage the formation of organizations of disabled persons at the local, national, regional and international levels. Their unique expertise, derived from their experience, can make significant contributions to the planning of programmes and services for disabled persons. Through their discussion of issues they present points of view most widely representative of all concerns of disabled persons. Their impact on public attitudes warrants consultation with them and as a force for change they have significant influence on making disability issues a great priority." [a]

Many organizations of disabled persons have already acquired a wealth of experience in the process of their formation, which they are in a position to share with newly developing organizations in other countries. The present document provides a set of guidelines for the development and support of organizations controlled by disabled persons. It is hoped that the guidelines will also be used to alert funders to the kind of assistance that they can fruitfully provide to these new organizations.

The assistance of the many organizations around the world that responded to the disability organizations questionnaire is gratefully acknowledged. The information that they provided in the comments to questions was particularly crucial in drawing up the guidelines, which were prepared by Vic Finkelstein, Senior Lecturer, Department of Health and Social Welfare, the Open University, Milton Keynes, United Kingdom of Great Britain and Northern Ireland, under a special service agreement with the United Nations. Financial assistance was provided by the Voluntary Fund for the United Nations Decade of Disabled Persons.

Notes

[a] A/37/351/Add.1 and Corr.1, annex, sect. VIII, recommendation 1 (IV), para. 65.

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PART ONE. MAKING A BEGINNING

PART TWO. ORGANIZING

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PART ONE. MAKING A BEGINNING

I. BACKGROUND

Introduction

Organizations of disabled persons have been growing rapidly during the past 20 years and are increasingly being recognised by national and international authorities as important channels for the voices of disabled persons themselves. Following the International Year of Disabled Persons in 1981, the United Nations initiated a number of projects in support of these new organizations. As part of its contribution to the United Nations Decade of Disabled Persons (1983-1992), the United Nations has supported the preparation of the present text in order to provide guidelines for the establishment and continuation of organizations of disabled persons.

These guidelines have been prepared on the basis of the responses to a questionnaire that was circulated by the United Nations during 1988 and 1989, as well as the comments and suggestions received from a large number of local, national and international organizations of disabled persons. The questionnaire was concerned with identifying the success and problems disabled persons had experienced in setting up new organizations. Questions were also asked about the problems encountered in maintaining such organizations and future plans.

The intention was to be able to offer nascent or new organizations some guidance on the type of issues that they should consider when starting an organization or existing organizations assistance in continuing and improving their work.

The questionnaire was sent to organizations that were known to be active and that had had contact with the United Nations. They were advised that the information they provided would be used to help disabled persons starting new organizations. They were asked: to identify the nature of their organizations; the problems that they faced in starting or maintaining them; and the kind of help that could have assisted them when setting them up.

The response to the questionnaire was excellent, showing that organizations of disabled persons are very willing to help each other in their development. Many questions had been designed to provide an opportunity for comments, suggestions and advice as well as for gathering quantitative data.

Of the 120 questionnaires analysed, 69 per cent of the organizations were formed in the period 1970-1990. The membership of the majority (68 per cent) included both able-bodied and disabled persons. Although most organizations (59 per cent) were controlled by a management committee of able-bodied and disabled members, in most of these committees disabled persons were in the majority.

A. Frames of reference

One of the problems in analysing the questionnaire was how to interpret different approaches to the same question; for example, quite a few respondents indicated that their entire membership comprised disabled persons, but added that this assessment included the able-bodied parents of disabled children. However, not all representative organizations of disabled persons would interpret such entities as being organizations of disabled persons. Clearly, there is a need for some agreement about what is meant by an organization of disabled persons. Other questions, too, occasionally raised problems of interpretation. Central organizations with regional branches were sometimes recorded as federal or other bodies. Problems in interpreting type of membership or type of organization are not just linguistic disagreements but the product of real differences in the frame of reference and perceived goals of different organizations.

B. Aims of the guidelines

Information on problems in setting goals, deciding priorities for action and gaining support for the work of the organization was also sought in the questionnaire.

While there seemed to be universal agreement that organizations controlled by disabled persons are needed, the answers to the question about organizational aims and objectives would suggest some lack of clarity on the part of the respondents as to why their organizations had been set up and what they hoped to achieve.

Sometimes the aims given were very obvious (such as "to improve the condition of disabled persons") but too vague to point the way for action planning. Sometimes respondents included several different aims, which made their goals confusing; for example, "improving rehabilitation" might have been combined with "attracting funds for research to cure genetic or acquired disorders", "improving the supply of equipment" (such as wheelchairs) and "national campaigns for citizenship rights". If organizations are not clear about their aims and objectives, they can easily be forgotten or it can be more difficult to decide what action should be taken when resources are limited.

The intention of the the present text, therefore, is to provide a set of guidelines for disabled persons who are thinking of starting a new organization or for the members of existing organizations who feel that they would like to review or improve on their current organizational aims and structures. The aims of the guidelines are:

(a) To discuss the concerns that might be considered when starting an organization controlled by disabled persons;

(b) To stimulate a discussion on the purpose of starting an organization and what it might achieve;

(c) To encourage critical thinking about organisational aims and objectives and how these should be used in the day-to-day operation of the organization;

(d) To point to the importance of regular reviews to evaluate organisational progress in achieving aims and objectives and of mechanisms to involve members in the revision of the organisation's goals, if necessary.

II. WHY FORM AN ORGANIZATION?

A. Identifying barriers and needs

The remarkable growth of organisations controlled by disabled persons suggests that disabled persons are much more willing to play a greater role in their own affairs. One reason for this development has been increasing dissatisfaction with the gap between the quality of life felt to be possible and the limited successes achieved by disabled persons. The most immediate result has been the voluntary gathering of disabled persons into organisations to make their basic needs known more forcefully to Governments and providers of services. Increasingly, disabled persons in these organisations appear to see their needs linked to a campaign for civil rights. It is now felt that a medical condition does not have to result in the person affected having a low social and economic status. The non-involvement of disabled persons in their communities is increasingly seen as being caused by barriers in the physical environment as well as by barriers resulting from low social expectations or traditional social customs. The overcoming of these barriers is regarded as the main priority for the next few decades.

New organizations of disabled persons are needed for several reasons:

(a) To provide a focal point for the expression of the voice of disabled persons in their own affairs;

(b) As a forum for discussion and enlightenment amongst disabled persons on the identification of barriers and how these can best be challenged and removed;

(c) As a pressure group to redirect services away from custodial and caring activities to those that would effectively remove barriers in the community;

(d) As a channel for rethinking and planning (and, increasingly, the provision) of support systems to enable all, including severely impaired, disabled persons to live active lives in their own homes and societies;

(e) To campaign for improved medical services.

The democratic involvement of disabled persons in the design, planning, implementation, provision and maintenance of disability-related services is perhaps the most significant development that has led to the growth of organisations of disabled persons in recent years.

B. Acquiring an identity

Historically, the principal approach to disability was that of making disabled persons "normal" or encouraging them to behave as "normally" as possible. The final objective was integration into society. In practice, this meant that interventions were based on two simple assumptions about disability; first, that the problem was medical and the ultimate solution was the discovery of a cure for the physical ailment; and second, that if a disabled person could not be cured, then the goal should be to provide care so that he or she could integrate (actually, assimilate) as far as possible into the existing able-bodied community.

After the Second World War, important developments in medical approaches to disability were made. While new medical technology and improved preventive techniques helped to reduce the incidence of permanent impairment in the population, they also led to a greater survival of babies born with physical defects as well as of adults injured through an accident or illness. The numbers of disabled adults with lasting physical and mental impairments seems therefore to have increased. Consequently, disabled persons have felt the need to get together in groups where they might share their problems and discuss possible solutions.

Of immediate concern to most disabled persons is the inadequate provision of medical services. When they are available, however, disabled persons question their dominance over their lives in the community. In order to develop campaigns on these issues disabled persons have begun forming a wide range of organisations.

The willingness of disabled persons to meet and discuss mutual concerns has gradually promoted an improved public image of disability. There has been a re-examination of campaigns for integration and a greater uncertainty about programmes aimed at assimilation. There is strong support for the view that the most effective path to integration could be by promoting the acceptance of disabled persons as a separate social group with its own identity. This growing identity, in turn, has stimulated the growth of organizations of disabled persons.

C. Tackling the issue of services

Amongst the issues provoking lively discussion in the new organizations is that of the State-run and voluntary services that can support disabled persons living in their own homes rather than in institutions.

Absence of services

There seems to be widespread agreement that effective medical programmes for improving the health of disabled persons are under-resourced, with too few staff and facilities. Progress is needed in medical treatment, physiotherapy and occupational therapy, as well as funding for research into cures for different types of impairment. Campaigning for State funding to increase services has often been one of the first reasons for setting up organisations of disabled persons; frequently, organisations start with this aim and then move on to other objectives.

Inappropriate services

In general, the medical approach to disability has involved the development of a range of services and professions concerned with treating or assisting the persons affected. While one of the first aims of the new organisations has been to improve access to individual medical services, there has also been growing concern that individualised approaches to disability can lead to the suppression of the citisenship rights of disabled persons. Global medical interventions, in the context of citisenship rights, are increasingly felt to be inappropriate and organizations of disabled persons are campaigning more for the right to be democratically involved in their own affairs (e.g., to campaign for legislation on access to public buildings and transport systems).

Agreement that many current services for disabled persons have inappropriate goals is another reason why disabled persons are setting up their own organizations, either to campaign for new services or to start providing their own (e.g., centres for integrated living or centres for independent living).

Charities

Traditionally, non-medical organizations concerned with disability have been set up, often with little involvement on the part of disabled persons. These organizations generally aim at setting up facilities for the care and welfare of disabled individuals, and an important feature is the way in which they attract funds from the public by showing disabled persons as dependent, passive persons who are unable to cope on their own and who lack ideas. Charities are often regarded as the single most important influence behind the negative perception of disability by the public. In many cases, the new organizations controlled by disabled persons have felt the need to criticize publicly the image of disability promoted by charities, and there is much controversy about their accepting money from charities in order to develop the new groups that promote a positive image of disabled persons.

Models of good practice

The growth of organizations and services controlled by disabled persons has led to an improved exchange of information between groups of disabled persons in different areas of a country as well as between countries. There is an increased awareness of examples of good practice in different parts of the world. Improved access to international travel has also made it possible for disabled persons to visit different centres and to exchange ideas with other groups, which has further encouraged the development of organizations to start projects following the examples of good practice noticed elsewhere.

There is growing agreement that issues focusing on disability in the community are related to barriers in the social and physical environment; that these are citizenship and civil rights issues rather than medical problems; that organizing as a distinctive group can be a way of integrating its members into society; and that dissatisfaction with current services and charities, and new ideas about support systems and increasing examples of good practice, have all contributed to the urgency felt by disabled persons to form themselves into organisations for the rapid promotion of change.

III. WHAT TO CONSIDER IN FORMING AN ORGANIZATION

A. Agreeing on first priorities

Organisations of disabled persons are usually started by small groups of people. These individuals will probably have been active in campaigns for improved services or they may have had an opportunity to visit other countries to witness organizations acting effectively in similar campaigns. Sometimes providers of services see the need for organizations as a result of their wider contact with parents and disabled persons. Sometimes parents agitate for improved services and form organizations for the welfare of their children. Later, when these children grow up they may become active in the organisations and perhaps eventually come to control them.

The first small group of people will usually have some ideas about why an organisation is needed. Often, it is simply to involve more people so that campaigns can be more effective. However, new members joining an organization do not always have the same views or understanding as those who started it. People who set up new organizations, therefore, may have to rethink their original objectives to ensure that they make sense to a wider membership than the original small group of founding members.

It is perhaps common when preparing the aims of a new organization to forget about identifying priorities and time-scales for reaching goals. Often the main concern is to identify aims that will attract a large membership, which may mean missing the first stage of identifying immediate tasks and clarifying proposals about how they can be achieved. Once the organization is inaugurated, initial pressures to promote it and to attract members may further delay setting priorities for work. As the organization responds to concerns regarding government legislation, inadequate services and the demands of members, taking time to identify priorities and plan time-scales for action may recede further from sight.

Setting organisational priorities and time-scales for their achievement can provide members, when an organisation finally comes into being, with criteria for judging its effectiveness. They can also give people an indication of when an organisation has served its purpose and is no longer needed (i.e., when its objectives have been reached). Organisations often continue long after they have achieved their goals, or have moved away from their original goals, mainly because people can be reluctant to relinquish social contacts established over many years of working together. In such circumstances, it is possible for an organisation to lose all sense of direction, which cannot only cause confusion among the membership but also lead to endless arguments between individuals about the work that the organization should be doing.

It is important, therefore, for individuals thinking about starting new organisations to record and to discuss why they want to start a new organization, what they hope it will achieve and how soon they want it to attain its goals.

B. Setting aims and objectives

In the surge of activity to start an organisation, often because of an urgent need to demonstrate that a campaign is supported by large numbers of people, impatience can arise when time is spent in discussing aims and objectives. Misunderstanding about the important role of organisational aims can lead to the weak drafting of a set of aims and objectives that offer no guidance for action. Decision-making may thus fall heavily on the leadership, and an élite can easily emerge. A well-prepared list of aims and objectives should be carefully recorded for guiding united action and promoting democratic working practices.

At least one early discussion, therefore, before setting up an organization, could be devoted to clarifying the reasons why statements of aims and objectives are needed and how they will be used in monitoring the procedures to run the organization. A useful exercise for those involved in setting up a new organization would be to list the important aims that they believe should be adopted by the organization. These should be shared and the ensuing discussion should then focus on ways of making regular use of the agreed aims to evaluate individual activities carried out in the name of the organization.

The ability of an organization to listen to the wishes of its less articulate members can often be measured by comparing the organization's aims with the actual involvement of such members in its decision-making. Aims should be set out in a way that make clear the purpose of organizing. Objectives should clarify for the members their expectations in achieving the overall aims. Both aims and objectives should make realistic sense to the membership rather than be worded in vague or obvious terms (e.g., "to improve the welfare of disabled persons"). Carefully worded aims and objectives may stimulate ideas about what needs to be done at different stages in attaining an agreed goal.

C. Deciding on the membership

The character of an organization is not only determined by the way in which it is organized, and its aims and objectives, but also, to a large extent, by the nature of its membership. It is vital, therefore, for those starting an organization to think very carefully about the interests that it might best represent. This should be made clear in the aims and will help to finalize decisions about who can join the group. For instance, organizations may establish aims concerned with issues related to only one type of impairment, which will suggest that only persons with that impairment should join the organization. Sharing ideas with others who have had slightly different experiences, however, can sometimes lead to exciting new ideas.

Whatever the composition of its membership, an organization of disabled persons needs to recruit and develop an active campaigning membership in order to avoid reinforcing attitudes that assume that disabled persons must be passive. In many ways, this awareness could be an important principle for the daily activities of the group. Education programmes to help members appreciate the value of developing a confident social identity can challenge important stereotypes and, in turn, reinforce the confidence of other disabled non-members. Once there is some awareness about the type of membership that will be recruited, it may also be helpful to have some idea about the possible eventual size of the organization: government statistics on population groups could indicate how many people would be eligible to join the organization. Any tendency to recruit only people from the same social background and geographical area probably should be avoided so as not to encourage the formation of an élitist group in the disability community.

Offering new members the opportunity of taking part in leadership training can help to spread workloads and to increase areas of responsibility in decision-making. The aim should be to engage as many members as possible in the work and decision-making of the organization and to avoid conflicts that divert attention away from its aims and objectives. Conflicts between different disability groups (e.g., wheelchair-users setting priorities concerned with mobility and ignoring the communication needs of members with sensory impairments) are not always avoidable but need to be discussed openly and interpreted in relation to the organization's aims. The recruitment of able-bodied members can be another area of conflict. Sometimes able-bodied advocates join organizations in support of persons with learning difficulties but then face hostility from other disabled persons. In all these situations, the constitution and overall aims and objectives should guide discussions about working relationships so that the organization's goals remain clear in the minds of all those involved.

D. Gathering members together

The task of setting up and running an organization of disabled persons often involves overcoming a variety of barriers to ensure the active involvement of the membership. Apart from financial resources to cover expenses, such as recording documents on tape and transcribing them into Braille and providing sign-language interpreters, etc., it is vital for organizers to anticipate all the difficulties that might prevent members from working together.

Organizations that include members from rural areas usually encounter difficulties in bringing people together. It may be useful to rotate meetings so that although not all the members will be able to attend all the meetings at least all of them will have some opportunity of taking part in the discussions. Sometimes lengthy discussions can take place through a newsletter that circulates between members, but not everyone is comfortable with this form of communication. It may be necessary to list the barriers faced by individual members in particularly isolated areas, to decide on priorities for separate funding applications and then to tackle them one by one, for example, making sure that a helper is available to assist a member at meetings held in the local area, and covering the costs of transport for another member in a different area.

With limited resources, priorities should be clearly identified for all to see so that no decisions are made without a discussion. No member should feel at a disadvantage in the allocation of resources. When the skills of a disabled member are particularly needed and resources have to be made available to enable him or her to work for the organization (which might entail, for example, the purchase of an item of visual equipment) all those involved should be aware of the reasons for the ensuing expenditure. Bringing different groups of disabled persons together may require a lot of time and energy and where conflicts exist between different groups, problems can quickly become unmanageable. Usually people will be willing to sort out their differences, especially when they can agree on common long-term goals. If discussions concentrate on agreeing on ways of reaching the organization's goals, short-term conflicts may be easier to put aside.

E. Making decisions

During the formative stages, when the numbers of people involved in steering groups may be small and few resources are available, people can be confused about the decisions agreed, namely, what needs to be done, who is to do what and by which date. Decisions on matters such as fund-raising, preparing the constitution and publicity for the new organization should therefore be recorded and circulated and taken in a series of distinct stages. The first is to make sure that questions about setting up the new organization can be answered in a practical fashion, leading to action plans, rather than in vague terms. The second is to make sure that the people with the right skills are working in the areas where they can offer most. Some people are particularly good at writing documents; the drafting of a constitution can draw on such skills. A third is to ensure that good records are kept, outlining the discussion leading to each decision. Each decision should be separately recorded with an indication of who is expected to carry out the work and the date set for its completion (e.g., the agreement that a publicity leaflet should be prepared for a consultative meeting should be recorded and the name of the person preparing it noted; dates for circulating the draft leaflet should also be recorded and follow-up meetings planned). These records should be accessible to everyone who participates in starting the new organization.

A good way of making sure that nothing is forgotten at the early stages when people are still unsure of their abilities and of what needs to be done is to bring everyone together for an hour or so in order to prepare a comprehensive check-list of things to do. This list should then be discussed and notes taken about the order in which the jobs are to be done. Once these priorities have been agreed, individual members should be entrusted with tasks of their own.

PART TWO. ORGANIZING

IV. FIRST STEPS

A. Defining the organization

Before embarking on the work of creating a new organization of disabled persons, it is worth considering why such an organization could be needed. This process should lead to the formulation of clear proposals for action.

Question to think about: Why start an organization of disabled persons?

At first, this question may seem rather foolish. Once a group of people are already meeting and discussing the importance of disabled persons having a voice of their own, as well as calling for changes to local and national community-based services, they are beginning to exercise basic citizenship rights. This goes beyond the formation of reactive responses to unsatisfactory conditions. Starting an organization cannot only be a way of taking the initiative, but also of setting in motion a new set of social and personal relationships with long-term outcomes that are not predictable.

Activists do not necessarily get everything right and the uncertainty of starting something new can provide an opportunity for all those involved of thinking carefully about the interests they represent and the needs that they are trying to meet. Asking why a new organization is required should encourage more discussion on these basic questions: Whose interests will be expressed in the new organization and will it meet their needs? Are the goals that are being set for the organization also practical and useful to the needs of other disabled persons who are not active or who do not have the opportunity of being active because, for example, there is no accessible transport.

Some examples. The number of organizations created by disabled persons are growing rapidly and vary in type and purpose from national coordinating bodies set up to prevent the duplication of effort and to share ideas to arts organizations set up to improve access to national theatres, cinemas, galleries and museums. Yet another type of arts organization, for example, might wish to promote the separate identity of the disabled and to develop art forms in forums specially for the disabled.

With all this possible diversity, it seems particularly important to take careful steps to ensure that as many disabled persons as possible (locally or nationally) can take part in the discussions about why an organization is needed, what its functions might be, what it hopes to achieve, who can join it and how it will be run.

What to note. Democratic participation in the preparation of an organization's constitution (defining the organization) can be a significant way of becoming clearer about its role. Preparing a check-list of important issues can be a useful way of making sure that they are not overlooked.

Membership involvement

It is important to ensure that all practical steps are taken to solicit the views of as many people as possible who are potential members of the organization. Such information may be obtained by using questionnaires, discussion groups or interviews. Information should not be one-way and efforts will have to be made to ensure that everyone can obtain sufficient information to give knowledgeable opinions about forming new groups. Policy discussion documents should be widely circulated and feedback allowed from any of the working groups, small committees, individuals or larger consultative meetings.

When meetings are convened, questions related to access have to be considered: whether people can reach the meetings, read the documents (Braille, tape, presence of readers) and participate in the discussions (sign-language interpreters). At the end of a meeting, too many views can be difficult to integrate into a single policy document: it may become necessary to decide when to stop gathering views.

Suggestions such as these need to be brought to the attention of those, usually only a few, persons who are responsible for drafting the documents, which are usually returned to the various working groups and committees for further comment before being submitted to the main membership for approval.

Unity of purpose

One reason for being very clear about why an organization is being set up is so that all those involved can see what they are doing and can decide whether they support the organization. This process also encourages clarification of the steps to be taken to reach the final goal. It should then become possible for all members to focus on being successful in reaching a first goal before moving on to the next. Trying to jump from the early stages of development to the final goals usually means missing out vital democratic steps and ignoring the need to keep the membership involved in the discussion about the organisation's development.

Drawing up rules for participating in discussion are important ways of trying to ensure that all members can take part. They also provide a framework for decision-taking (e.g., by majority vote, two-thirds majority, proportional voting, etc.).

Democratic procedures encourage members to follow the decisions of the majority, even when an individual is not fully in agreement, until a stage has been reached where processes can be reviewed. When it has been decided that an organization is needed, it will be necessary to ensure that people are clear about how it should be set up. Unity of purpose is very useful in moving tasks forward and understanding the different phases in the development of an organisation. Some of those phases might be: (a) calling a consultative meeting of interested parties; (b) setting up a steering group; (c) preparing drafts of various documents; (d) reaching agreement about such working papers; (e) circulating them for further comment before final drafts are prepared; (f) convening an inaugural meeting at which the constituting documents are reviewed and sent to working groups for finalization; (g) formerly adopting the constitution; and (h) electing officers. The organizational structures thus agreed on are meant to enable decisions to be taken and ongoing reviews to change policy directions to be made and to improve the efficiency of the organization's work.

Long-term strategies and short-term tactics

Often long-term and short-term aims are confused when people realize that some goals cannot be achieved immediately. There is a tendency to drop longer-term goals and, after a while, to forget that any had been set. Short-term objectives sometimes seem less important, do not attract members' attention, and are not met. An organization may thus never move closer, step by step, to the achievement of its overall goals.

For example, if a longer-term goal is to increase the pressure put on Government to fund moves towards making all transport accessible, sub-goals might involve attracting funds for private transport, using this transport to convey members to meetings, preparing and discussing documents at these meetings and finally taking members to where they can lobby the authorities for the changes that are wanted.

If goals are linked together in this kind of a chain then it may be necessary to involve all those persons starting the organization in the task of preparing a check-list of action required. Check-lists enable people to see which tasks have been completed and which still need to be undertaken and they can be valuable tools at the early stages of developing an organization when people are still unsure about what needs to be done.

Check-list

We need an organization of disabled persons because it will:

- Help to obtain civil rights legislation;
- Mobilize disabled persons;
- Improve public transport;
- Help people to find jobs.

B. Constituting the organization

All too often, members spend a great deal of time arguing about and perfecting a constitution which, once the organization has been formed, is hardly looked at again.

Questions to think about: Why have a constitution?
What purpose is served by a policy document?

Some examples. A constitution can give legal status to an organization and the way in which it functions (e.g., who is legally responsible for the money collected). The constitution sets out the structures for carrying out the organization's work and is a policy document guiding the action of its members.

Some additional thoughts. Use the constitution whenever possible and encourage members to become familiar with its contents. The document should provide guidelines for structuring decision-making and action plans.

What to note. Members should be clear about the principles governing their involvement in the organization and the organizational structures laid down by the constitution for achieving this involvement (e.g., role of councils, management committees, branches). The constitution should provide a ready point of reference for calling members to order (including the leadership). One of the most important advantages of having a constitution is to ensure democracy and to have a tool for grass-roots access to the working and decision-making bodies of the organization. A constitution should cover:

the name of the organization; the definition of eligibility for membership; the type of membership; subscription; officers and roles; decision-making bodies; executive bodies; branches; annual general meetings; emergency meetings; workshops, seminars, conferences and other meetings; publications; fund-raising; registration under national legislation (e.g., as a charity or a limited company); the frequency of meetings; dissolution arrangements (the dispersal of funds, debts and property); the recruitment of paid staff; rules for debate (sometimes attached as a separate document); and relation of the constitution to policy documents. It may be useful to prepare a check-list of the proposed contents of the constitution before starting to draft it. Sample constitutions from other organisations (or even other countries) can be helpful in preparing the new documents.

Check-list

We need a constitution so that:

- Officers will report back to the membership on the outcome of their actions and explain the responsibilities they have undertaken in the name of the group;
- Information will be regularly passed on to members.

C. Recruiting members

The question of who to recruit into an organization of disabled persons is usually fairly open, within certain broad limits. Sometimes there can be difficulties, as indicated in this section.

Questions to think about: Who will benefit from the organization's work? Who needs to become involved with the organization to make its work successful?

These two questions sometimes puzzle organizations and can lead to difficulties. A charity's goal of helping the poor may mean relying on recruiting rich members to the organization for the funds that they bring. In this case, there seems to be no point in recruiting poor people into the charity. However, if poor people are not involved, they will continue to remain passively dependent upon the good works of more wealthy persons.

Organizations are usually started by small groups of people who are highly motivated; frequently they will be able to contribute some of their own resources to bring people together. The reason for founding an organization, however, is often because of concern about the welfare of others who may be less fortunate. Since the focus of attention is on the poorer group while the work is carried out by disabled persons in more fortunate circumstances, it may be easy for the latter to believe that they have the interests of the poorer group in mind, even when they stray from their real needs. It is important not to lose sight of those for whom the organization was set up to help. The persons who are meant to benefit most from an organisation are not always the same people as the founders.

Some examples. Parents may start an organization to help their children, with the aim of making the children "as normal as possible". However, this organization could come into conflict with other disability groups in the arts where the aim is "to celebrate differences".

Some additional thoughts. It is important in setting up an organisation to ensure that the intended beneficiaries are fully consulted and have a direct say in the way in which it is set up and operated. Vigorous measures may have to be taken to ensure that less fortunate disabled persons are given every opportunity of participating in setting up the organisation and discussing its relevance to their future well-being, even if others are going to be doing all the work. For example, disabled persons in urban areas can meet together more easily than disabled persons in rural areas but the main concern is often the welfare of those living in rural areas. Special recruitment drives in rural areas and campaigns to obtain funding and helpers could be initiated to enable these persons to be recruited and to participate in running the organization.

What to note. Recruiting urban people is often easier, through news-sheets, bulletins and pamphlets that can be sent to people's homes and meeting places. Radio and television are important ways of publicizing an organization but word of mouth might be more important in rural areas. It is often essential to spend some time in clearly identifying the groups to be recruited into the organization and then in identifying their common ways of receiving information in their communities. It is probably better to plan recruitment over a period of time; for example, by sending outreach workers to spend some time in the districts, rather than by promising grander schemes such as festivals. Poster campaigns can usefully target areas. The choice of methods of recruitment should be based on the constitutional aims and guidance laid down for membership.

Type of membership

There are many types of membership and organizations seldom recruit only one category of members. It is common to have some kind of mixture (for example, of disabled and non-disabled members). It is important for the efficient running of the organization and the achievement of its aims to be clear about who should join and the status that each subgroup will have in the organization.

The question of whether membership should be open only to disabled persons or to both disabled and able-bodied individuals is often uppermost in people's minds. Another question is that of age; namely, whether children as well as pensioners can join. Organisations also vary in whether they are open to mass membership or confined to those interested in specialist areas (e.g., in improving education or transport, in campaigning for a pension system for disabled persons or in supporting groups of disabled women). Membership may also differ for different groups of people; for example, full membership for disabled persons and associate membership for able-bodied people. Organizations are often started to improve the situation of specific groups of disabled persons based on type of impairment, such as deafness or spinal injury.

Any confusion about membership may be avoided by listing the groups that are eligible, defining them and setting out their voting rights (e.g., associate members usually do not vote) and their expected role in the organization (e.g., only full members can serve on the executive committee). It is important to make sure that there are no barriers that could exclude different groups from full participation in the organisation's work and the discussion meetings. For example, blind members may need agenda recorded on tape and/or transcribed into Braille. The presence of sign-language interpreters could slow the meetings down and yet it is essential that proper recognition is provided in meeting the needs of each member. When persons with speech impairments attend meetings, proper adjustments have to be made so that they, too, can express their views in the absence of pressure from others who may want to speed up the discussions.

Type of organization

Once the type of membership has been determined, it will be necessary to decide on the general structure of the organization. This matter has a lot to do with the aims of the organization as well as the way in which the involvement of the members in its work is thought out.

A mass organization will often mean a unitary, federal body with a central office that sometimes delegates work to regional or local offices. A federal body means that local branches have more autonomy in their activities while the central office usually has a clearly defined central role, such as representing the organization to the Government. Often other organizations join in to present a united voice on a specific subject, such as campaigns for pensions.

Local groups, however, are usually small urban groups with very practical aims; for example, arranging leisure and sporting activities. Regional groups can often cover rural areas and pursue practical aims such as supplying wheelchairs or books on tape, or craft work for individuals who would otherwise be very isolated. They may also be umbrella bodies that coordinate local groups and represent them at the regional government level.

National groups usually have more global aims such as influencing government policy and coordinating pressure on national legislation.

International groups are often concerned with sharing information and helping the less fortunate.

By asking different questions, such as those set out below, different kinds of membership may suggest themselves.

Check-list

The organization aims at helping:

- Disabled persons and able-bodied carers;
- Persons with spinal injuries.

The organization aims at working with:

- Disabled persons in rural areas;
- School-leavers preparing for their first jobs.

D. Raising funds

All organizations of disabled persons suffer from insufficient funding and spend a great deal of time in trying to secure resources for developing and extending their work.

Question to think about: Why is money needed?

In setting up an organization of disabled persons, a number of basic issues have to be tackled: finding an accessible place to meet and ways of transporting members to it; identifying the basic equipment needed by the organization for its survival and contact with members (e.g., telephones, minicomputers, etc.), devising ways of communicating effectively with members about meetings, and deciding who will organize them and what publicity campaigns are needed to attract more members and the attention of the public.

At the initial stage of its development, when the organization is small and its immediate goals are restricted by the numbers of persons who can be involved, a little funding can make a big difference in helping the organization to make a successful start. Unfortunately it often happens that well-wishers, the commercial sector, established charities or local Government provide seed money but as the organisation gains momentum and its financial needs grow they are unable to continue, considering that they have made their contribution and cannot give any more. As organisations become established and expand their activities, financial problems often become worse.

Applications for grants are a significant feature in the life of all self-help groups. It is very important to draw up applications for grants clearly so that possible funders can see: the objectives that the organization is proposing to achieve with the money and exactly how it will be spent; how the money will be managed; and who will carry out the work involved.

Initial funding to start an organization is usually in the form of a small grant (often from local government) and subscriptions from individuals or organizations, supplemented by a great deal of free time from the organising activists. The way in which charities present disability to the public in order to provoke maximum appeal can be a serious problem. Disabled persons are portrayed as dependent, passive and incapable; the public are encouraged to feel pity and to dig into their pockets for charity. Disability groups often struggle to change just this image, to show that disabled persons can work and not be dependent upon others.

When looking for funding, it is very important to calculate as exactly as possible how much money is needed for each activity of the organisation under the strategic aims so that each step on the way to the final goal can be budgeted with targets for fund-raising. For example, by defining what a quarterly journal might cost to publish, the organizers will then know how much money they need to acquire for this publicity activity (perhaps funded by subscriptions). Funding for transport is a very important item on the agenda of any disability organization. Sometimes lump sums for a van can be obtained from international sources because the purpose behind such a project is clear and the amount spent easily accountable.

Fund-raising exercises are undertaken by nearly all organizations when they are just starting. A social evening with a raffle is a common way of attracting small amounts of money sufficient to give an organization an initial impetus.

Setting up workshops to sell products for a permanent income is another activity that is quite widespread. However, seed capital is needed and it usually takes a while before such an enterprise is well enough established to achieve its goals and to function in the organization.

Some examples. Money is needed to print leaflets and to record tapes informing people of the inauguration of the new organization. There is also a need to employ an outreach worker to help disabled persons in rural districts to follow developments. However, as there are not enough funds to cover all the objectives, priorities have to be determined.

Some additional thoughts. Funding should always be properly managed and responsible individuals to control expenditure should be clearly designated.

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Initially, this means working out a budget for each project (whether it is a small leaflet or the setting-up of a permanent office) and then specifically allocating funds to each project. This also means being clear about priorities so that the starting-point is clear; namely, putting resources into recruitment and involving the new members before funds are spent on printing glossy newsletters. How money is obtained and spent is an important concern for all members and regular information on this matter can help a membership to feel confident that it is moving in the right direction and that the officers and full-time workers are following the wishes of the members.

What to note. Someone should have overall responsibility for supervising financial matters and someone should be responsible for fund-raising. The funds needed for each project should be calculated and listed in order of priority. Fund-raising for the project should come at the top of the list. As funds for each project are obtained, the focus can shift to the next priority. A check-list of the equipment required can be a good starting-point for fund-raising.

Check-list

Why is money needed:

- For Braille transcription?
- To employ an outreach worker?
- To carry out research identifying the barriers faced by older disabled persons who have retired?

E. Encouraging democratic involvement and avoiding élitism

All organizations encounter the problem of an élite group of people dominating the management of the organization, decision-making and discussions at meetings. Organizations of disabled persons are no different.

Question to think about: How can we make sure that the organization meets the needs of its membership?

The individuals who start organizations usually become the first officers of the organization and when an organization becomes successful and grows, these people gain a lot of respect. Sometimes the skills needed to set up an organization (hard work and lots of publicity) are not the same as those required when disabled persons start to join and need help in order to become more involved. Patience and educational skills may be more important in helping members to follow developments so that they, too, can play a more active role in the organization's work.

The initiators of the organization will also most probably acquire a lot of confidence as they see their original plans and suggestions beginning to bear fruit in the growth of the organization. This confidence can make some of them impatient with the uncertainties of the grass-roots membership. Often those who are able to join the front ranks already have an advantage over their less well-off disabled peers. They may have jobs and educational qualifications, or live in a favourable geographical area where there are resources available that allow them some degree of freedom to function in the community. Those joining the organization later may face more difficult barriers and problems.

A tricky decision, in order to try to counter the possible growth of élitism, is whether to put into the constitution a clause that restricts individuals from being office bearers beyond a fixed time limit. This may ensure that no person becomes too dominant in an organization but, at the same time, may deprive it of talents just when they are needed.

Some examples. Individuals who set up organizations may make close contacts with government ministers. As they become better known amongst the authorities, they can start receiving awards and offers of prestigious jobs. Important topics that should be discussed from time to time are: making sure that the interests of the grass-roots membership are always kept to the fore; and determining what the role of a leader should be. Setting up constitutional safeguards to promote democratic methods of working is another way of trying to maintain control over experienced leaders. This will probably involve measures to increase the numbers of members who have the opportunity of taking part in the organization's activities, which can give less confident members space to learn skills for arranging future events. Also members should be encouraged to rotate jobs, to retire and then to come back again from time to time.

What to note. From the first steps in setting up an organization each person should know what the other is doing and have ample opportunities for commenting on arrangements and decisions. It is most important to develop a style of working that becomes second nature to the organization; this means learning how to give and accept criticism in an open and honest way. Persons who chair meetings often have powers beyond those set out in the constitution of the organization and it is very important for members not to tolerate undemocratic behaviour in such settings. What might have started out as a simple error in judgement during a meeting may, unchallenged, become a style of chairing meetings. Speaking out and defending democratic procedures can help to prevent the alienation of members.

Another problem to avoid is sectional dominance, whether it be gender (for example, that all the officers are men) or geographical (that all the officers live in the same part of a city and members living in the rural areas have no representation on the decision-making bodies). There should always be a mechanism for changing the constitution so that if, for example, over the years only a small minority of women are on certain committees the constitution can change their composition so that they are more representative of the actual membership. Meetings should periodically give an opportunity to the membership of monitoring this kind of democratic concern.

Paid employees sometimes acquire considerable powers in running voluntary organizations on account of their familiarity with the way in which an organization is run on a daily basis. A voluntary member of the management committee, however, may only deal with the organisation's affairs on a part-time basis, which can lead the policy makers to rely heavily on the opinions and judgements of a full-time worker. Although the constitution will make it clear that the employees carry out the policy decisions of the management, a mechanism may be needed for dealing with disagreements between employees and policy makers.

Check-list

Is there a system for ordinary members to comment on the work of the organisation through:

- Presenting resolutions to the meeting?
- Participating in forums concerned especially for discussions?
- Having access to policy documents?

V. MAINTENANCE AND GROWTH

A. Making the constitution work

Once a constitution has been adopted and the organization has had some time in which to operate, it is common for this document not to be looked at again unless a crisis arises. Generally constitutions seem to work well in this situation, providing a legal framework to avoid any further problems, especially when an organization has to be closed down and its assets dispersed.

Criteria for membership also seem to cause little trouble except when new categories of members are needed. For example, when an organization has been set up by able-bodied persons for the welfare of disabled persons and circumstances change so that the disabled members run the organization, they may want to change the constitution so that the able-bodied members lose their voting rights. This approach would allow the able-bodied members to share their skills and expertise with the disabled members and, at the same time, would provide space for the disabled members to gain more experience in running the organization and to develop their own expertise and confidence.

A good constitution, however, will also clearly state the aims of the organization, which provide general guidance for its work and are often elaborated in policy documents. The constitution will recognise that policy documents are reviewed from time to time in annual general meetings, at which they are amended, altered, rejected or accepted as providing the main guidance for the next round of activities of the organization. It is important, therefore, for the organization to review its constitution and to decide whether the original aims have been met and whether they need to be revised.

If no progress seems to have been made in achieving the aims, it is probably worth looking at the structures in the organization to see whether they are inhibiting achievements. For example, one goal may be to encourage the greater involvement of disabled persons in decision-making about the services that they receive in their local community. However, if the organisation has a strong body of decision makers at its central office, they are not always aware of local needs, which might therefore never receive the attention needed in order to further the goals enshrined in the constitution. Changes that lead to more decisions being taken at the local level, with monitoring at the central level, might lead to a better balance and a better working relationship between the central and local offices.

Also, the way in which campaigns are undertaken to meet short-term goals might be undermining the long-term, or strategic objectives. For example, if the goal is to set up a pilot project to demonstrate to employers that disabled persons can work effectively, an initial campaign to attract funds to run a workshop might present a rather passive image of disabled persons and unintentionally leave a strong public impression that disabled persons are helpless and need care.

Another very important task of the constitution is to ensure that the organization is run democratically, which requires an understanding of the function of the constitution and of how to make it work for the membership. Holding short courses at which members at the grass-roots level can question the meaning of different clauses and discuss the reasons for their inclusion could ensure a more informed membership, capable of defending basic democratic rights within the organization.

A hope would be that members would learn from such an experience and apply the ideas to the community in which they live. A good way of improving the use of this important document is by adding commentaries and policy statements to it from time to time. In this way, the constitution can help to create a corporate identity and help to prevent the organization from being identified with an individual member.

Questions to think about: Why is a constitution needed? (Use a sample constitution and policy document to make a list of reasons; indicate how the policy document does, or could, refer to the constitution and help to highlight some of its clauses.) Is the constitution easy to read and available for discussion by the membership?

Some additional thoughts. A constitution provides a legal framework for monitoring the work of an organization in the name of its members. It cannot only help to define who can become a member, but also help to decide how to handle certain situations when problems occur (such as expelling a member who has behaved badly). Constitutions have a definite role in guiding the work of the organisation and in making sure that democratic processes are followed. In general, when democracy is not working in an organisation it is either because people are paying no attention to it or because they are using it to shape their activities.

What to note. The constitution should clearly define the membership and the powers it has in decision-making; all the working and decision-making groups should be listed, their membership identified and their powers clarified. There should be clear routes for ordinary members to influence policy and to take part in all the important decision-making. Financial matters, fundraising and spending should be clearly controlled and monitored so that members can see and understand that these resources are being put to use in achieving the agreed aims. Members should know what to do if the organization is disbanded.

Some examples. A constitution states that the organization will promote civil rights for its membership. The leadership decides to employ consultants to lobby parliament for civil rights legislation: the grass-roots membership is not involved as the leadership regards this work as highly specialized and as best carried out by authoritative experts. Can this activity meet the constitution's aims of promoting civil rights for the membership by leaving it out of the process to obtain these rights? Could members refer to the constitution in questioning their exclusion from civil rights campaigns; if not, is there a weakness in the constitution?

Check-list

Is the constitution clear about:

- The powers of committees and officers?
- How democratic procedures can be made effective?
- How the constitution will be made accessible to blind and all other members?

B. Fostering an informed membership

Making the constitution, and the organization of disabled persons that it serves, really work usually requires an active membership that is knowledgeable about the working of the constitution, its aims and the policy documents adopted under its guidance. Perhaps one of the most important activities that any organisation of disabled persons can undertake is the education of its membership. Constitutions often do not refer to this requirement and it may be useful to include clauses in it, to the effect that the officers will from time to time organize seminars, conferences, workshops and courses for its membership. This will help to ensure that, once an organization has been started, the more active and informed people who were involved in the process can share their knowledge with others. Thus an organization will acquire a life of its own and will not be tied to the activities of an outstanding individual.

Passivity amongst disabled persons has many origins: isolation, lack of education, inability to mix with others because of barriers and lack of help in exchanging views with others. All these factors are part of the reasons for setting up a disability organization. The failure to educate disabled persons about the relationship between their isolation and developing an understanding of how to remove the barriers that prevent the equalization of opportunities in the community can only continue their dependence on others. A good place to start is with the constitution; members can then be encouraged to contribute to the drafting of policy statements based upon the objectives listed in the constitution.

Questions to think about: Is the constitution always sent to new members as they join? Are policy documents included? Are new members invited to make comments? Does the organization hold regular workshops, etc., to develop policy, to explain the constitution and to update it? Does the organization promote leadership training so that more members can play a role in the governing bodies of the group? Are all papers circulated in a form that is accessible for all the members (e.g., tape for visually impaired members, auditory material in written form, provision of sign-language interpreters at meetings)?

Some additional thoughts. Sending constitutions to all members is one way of obtaining feedback from the membership. If it is difficult to read, complaints from the less experienced can encourage redrafting with more accessible wording and a sharper focus, which in turn could result in statements that are clearer about the aims and structures of the organization.

What to note. Sample documents should be perused to see whether the constitution and policy documents refer directly to the education and training of ordinary members so that they can play a greater role in the organization and a leading role in their own affairs. An annual programme of educational events should be drawn up and circulated and leading figures in the organization should be available to pass on their expertise. The organization should organize its exchange of information in such a way as to ensure that it and its office are accessible to all (minicomputers, no stairs, properly equipped toilets).

Some examples. A national organization may have to communicate with people with widely different backgrounds, education and impairments. Can the organization carry out this task? If it has to carry out publicity work, how effective is it in putting its message across and do the members have a chance of participating. Are the organization's leaders the only people who have an opportunity of travelling to interesting conferences and meetings?

Check-list

Does the organization:

- Spend time in educating its members?
- Spend more time on educating the public than it does on educating its members?

C. Deciding on priorities

Priorities for action should be set in both the constitution and the policy documents following from the aims that clarify the long-term, strategic goals and short-term, tactical objectives. The overall strategic aim of a group should be monitored from time to time to ensure that it remains relevant to the contemporary situation. Often circumstances will change so that the original goals are no longer relevant or even possible. In these circumstances, and when goals have been achieved, questions should be raised about the need to end the organization. People sometimes continue the work of organizations out of habit even when there is little purpose in carrying on. For example, a group aiming at improving local access might be overtaken by the work of a regional group with the same goals but operating more effectively with greater resources. The local group might then provide members with social opportunities, as well as with duties relating to access, and carry on with its regular meetings.

Tactics, too, frequently need to be changed but it is remarkably easy for members to stick to their usual ways of working even when there is a long history of lack of success. The presentation of written petitions to the Government often achieves little without any practical demonstration of support from a mass membership; but an organisation may continue drafting petitions rather than involving its membership because a leader has acquired skills in writing papers. Priorities, too, need to reflect the wishes of the membership and sometimes leaders can promote their own concerns rather than those of the grass-roots members because the consultation process between the leader and the members has broken down.

Question to think about: Does the organisation list its priorities for campaigns and action plans and circulate them to its membership on a regular basis?

Some additional thoughts. One way of trying to clarify the choices available to an organization and, at the same time, involve the membership in the decision-making is to ask people to rank the issues that they want tackled in order of priority. The choices of the executive or management committee could be circulated with explanations of how these choices were made. Members and leaders should exchange comments on these issues whenever possible. Often priorities for action are set by the demands of external events that lead the organization from one set of reactions to another. Sometimes this is so pervasive that there is never time for the organization to take control over its own destiny and set its own goals for action. Priorities are best clarified when people can see how one set of actions or objectives lead to the development of another so that the final goal starts to appear achievable through a series of systematic steps.

What to note. Whenever decisions need to be made, the constitution and policy documents should be referred to and the short- and long-term aims listed. These aims should be so ordered that there is a progression leading from one objective to another towards the ultimate goal(s). The lists should be circulated and comments invited; each activity should be costed so that people can also identify how much it might cost to achieve each objective. Move towards the development of a comprehensive plan. The setting of plans with long-term goals should also identify the dates for reviewing which objectives have been achieved by the dates set and which have not. Goals may then have to be rewritten. This process should help members to become increasingly involved in the work of the organisation because they can see what it is doing and how (unlike very many organisations that lose contact with their members when they employ experts to do the jobs for them). Sometimes setting priorities can be very difficult, such as choosing to put limited energies and resources into fund-raising before campaigning for more members.

Some examples. Employment for disabled persons in rural areas might first involve making contact with such persons and establishing ways of retaining this contact (by regular visits from outreach workers); afterwards a regular rural transport system will be needed to bring people together where information and educational programmes can be established aimed at identifying local needs, individual skills and initiatives, which can be explored.

Check-list

Does the organization have a long term action plan:

- That is circulated to members?
- For which there is a system for monitoring and changing priorities?

D. Handling operating expenses

Once an organization is established and attracts a growing membership, its operating expenses can increase dramatically and significantly impede further development. Organizations might spend so much time in trying to secure funding that they cannot tackle some of the other priorities that they may have identified.

Identifiable projects with clearly defined goals, such as setting up a workshop for a group of disabled members or carrying out research to identify ways of removing communication barriers in rural areas, are fairly easy to present to potential funders. However, secure funding to operate an organization's central and regional offices may be much more difficult to organise and may require regular fund-raising activities. Such activities vary greatly from country to country and need to draw on national, culture and local customs. Generally, individual subscriptions are never sufficient to run disability organizations. Disabled persons are simply not financially independent enough to carry this load. Although Governments contribute substantial amounts, many charities are competing for such funds, with the more established groups receiving large amounts and the new groups desperately trying to make a case. The fact that disabled persons are taking their destinies into their own hands means that organizations of disabled persons are being set up in places where there are well established organisations formed by able-bodied persons for the disabled. It is therefore essential for these organizations of disabled persons to make clear to funders that they are different from the older charities: as self-help groups, they are not seeking funds for caring for their members but for looking at ways of encouraging them to function independently in the community.

An important priority for funding is helping less fortunate members to attend meetings, to receive the literature and to pay for equipment such as wheelchairs. Organisations sometimes reserve funds to support members needing urgent help with equipment or travel etc. Graduated subscriptions are sometimes a method of sharing the costs of operating an organization.

Another common problem of organisations of disabled persons is their inability to pay going rates for their staff: they usually pay the lowest standard wages. Consequently, it can be very difficult to find skilled and motivated personnel to carry out projects, which, in turn, can put more pressure on the skilled voluntary workers and management committee members. The leading disabled persons can quickly find that they cannot keep up with the demands placed on them.

Questions to think about: Does the organization have a clear ongoing plan for attracting the funding it needs? Is that funding sufficient to maintain the operation of the organization?

Some additional thoughts. One way of ensuring that grants are sufficient is to include in the applications for them the budgetary estimates for the rent of office space, overheads, heating, lighting, water and depreciation of furniture etc., as well as for secretarial help, stationery, telephone, travel, meetings etc. By attracting funds for several projects, offices can be maintained for several years.

What to note. It is vital to keep a calendar showing when all funded projects start and end so that new applications for grants can be submitted well beforehand in order to build on the work of earlier projects. Otherwise, management and staff may have long periods of uncertainty about future developments. In the case of an income-generating project (such as operating a wheelchair-repair service for local government), all those involved need to know on what the income is to be spent. Shifting income from viable projects, such as workshops, to less tangible ones, such as providing education and training for individual disabled persons, is important but can cause a great deal of resentment amongst those who work hard and do not receive a full return on what they produce.

Some examples. Funding from an international donor can often help key projects to make a successful start. Care, however, has to be taken to ensure that the projects represent what local disabled persons want rather than what the donor may see as being important. The local organization should therefore set out its objectives very clearly with an explanation of why it has chosen to target on a particular project. Satisfactory arrangements for both donor and recipient to monitor the project are always important.

Check-list

Has the organisation needs identified its annual running costs to see:

- If these costs can be covered by Government grants?
- If these costs are always included in applications for grants?

VI. NETWORKING

New organizations of disabled persons devote much time to searching for information and resources. When an organization is first starting operations, examples from other organizations starting on the same road can be extremely helpful. Most organizations will have had some previous contact with other groups, which provided them with the experience to go ahead and to start their own new organization, but networks amongst disabled persons are still underdeveloped. Networks not only provide examples of good practice and models for action plans, but also suggestions for access to resources, for example, whom to approach for funding or for voluntary workers to help an organization at the initial stages.

Often small local groups are unaware of the extensive network of organizations of disabled persons. They may not know that there is a national body that can arrange contacts, send speakers and provide advice. Sometimes it can advise on grant applications and supply supporting arguments for them.

Once organizations are established, they will start to make contact with other like-minded organizations, to share ideas and to lend each other emotional support. Sometimes, however, organisations compete for scarce resources and duplicate each other's work, especially when new organizations are set up in areas where established ones have been operating for some time. Organizations need to set aside time for making contacts and deciding on priorities for information and support in order to target their activities.

A. Local activities

The local level is often where the most important direct contact is maintained with disabled persons, where information is exchanged and individuals acquire help and knowledge directly affecting their lives. At this level, too, an organization can be made or broken because the way in which the membership at large receives its work shows whether or not its aims are relevant.

In order to work effectively at the grass-roots level, it is usually vital to employ development workers who can move into the community, trace individual disabled persons and make contact with them and their families. Going into the homes of disabled persons is not always possible, partly because they may not be known in the first place and partly because this might overtax scarce resources. A frequent practice is to try and attract disabled persons to a specially organized event, such as a sports day for disabled persons, and to use the occasion to register and attract people into the organization. Posters advertising the event in doctors' clinics, market-places and on local radio may help to gather many people together. Sometimes single events will attract people, even when there are transport and access problems, because they are very keen to make contact with others. In any case, it is a good practice to try and arrange back-up transport with contact points for those who wish to attend but who do not have the means.

The involvement of an organization's leaders at local events can be very important. Disabled persons with experience often have practised arguments to motivate people and to encourage them to join the activities of the organization. Shy and withdrawn individuals can be helped by meeting confident leaders who can be seen to be in control of their lives. Always, however, there is the need to present to potential new recruits clear goals that can be easily understood. There is little value in arguing that civil rights legislation is the main agenda for campaigns when individuals cannot follow the arguments because they have not had the benefit of basic education or because they cannot come to meetings on account of ill health or lack of transport. Working with individuals at the local level provides a solid base of ongoing activity to feed into the development of more global plans and visions.

Difficulties of access in local communities can sometimes encourage organizations to employ able-bodied outreach workers but this may mean that the wrong message is given to the community about what disabled persons can do. Difficulties in working locally with individual disabled persons can encourage organizations to seek more dramatic changes by working as pressure groups for changes in government policy. This in turn may result in prestigious projects that nevertheless leave local people just as isolated and dependent as they were before.

Question to think about: Does the organization have plans for ongoing continuous work at the local grass-roots level?

Some additional thoughts. Check membership application forms to make sure that local disabled persons can record their perceived needs and what they want to be involved in. Do they want to receive visits from the outreach worker, or to visit the office or other facilities of the organisation? Are there ways of linking individuals together at the local level so that they can develop self-help projects based on examples from elsewhere?

What to note. Members from the various local levels should be represented on the management of the organization and information should flow freely from the local level and back. If the organisation is centrally controlled, there should be adequate forums for people to become involved, and to share ideas at the local level (perhaps local branches would be useful). Information in Braille and on tape and sign-language interpretation are very important to enable real access to facilities and to demonstrate what is possible.

Some examples. An organization has set up a local training office to give advice and support to disabled persons seeking employment in the town or district. The office keeps all the relevant information about jobs and accessibility. The organization also makes regular contact with local businesses and gives talks at local meetings about changes that disabled persons would like to see in the community.

Check-list

- Are members from local areas represented on the management of the organization?
- Are disabled persons also working at the local level?
- Does the constitution encourage direct interaction with local branches of the organization?

B. National roles

National bodies often include local-level branches and act as coordinating bodies, especially in seeking government support for developing job openings locally. In industrialized countries national bodies may also help in persuading large industries to recruit disabled persons.

Campaigns to put pressure on the Government to allocate resources to local government, etc., however, call for skills quite different from those needed in working directly with disabled persons. Pressure-group work often involves working alone to prepare documents for submission to the authorities. While it is important, statistical work can be so specialized that leaders may lose sight of their constitutional aims so that the organization increasingly puts its resources into making arguments rather than into working with and involving disabled persons. A key question is whether the organisation constitutes itself as a policy body, involved in educating the public and changing attitudes, or as a provider of its own services.

At first, services usually mean counselling and advice-giving, which may expand to preparing booklets for self-health management. Sometimes national bodies are concerned only with specific groups of disabled persons, such as spinally injured and deaf persons. In this case, the goals may be very specific; for example, to campaign for sign language to be recognised as a national language and to ensure that all deaf persons have an opportunity of learning sign language in school, if they wish. The organization may also keep lists of sign-language interpreters who can be recommended when needed. National organizations frequently publish newsletters, which provide a vital function in exchanging information, illustrating examples of good practice and putting people in touch with each other. Changes in perceptions of disability can also be aired in journals and news-sheets. National conferences and publicity campaigns usually form part of the schedule of organisations, aimed at providing a more progressive climate for the work of local organizations. National research projects can also feed into the networks and link different groups together so that a united approach can emerge that promotes disabled persons as being much more involved in their own affairs.

Questions to think about: If the organization works witn a national body, does it have clear links with work at the local level and do those links involve the leadership from time to time in direct contacts?

Some additional thoughts. From a strategic point of view, the links between national and local organizations can form a very powerful lobby in changing overall attitudes and in providing the right climate for steady but deep changes in the situation of disabled persons in a country. Because of isolation, confused goals and a lack of skills, disabled persons in different organizations can often find themselves in conflict. The traditional view that disabled persons cannot cope without the help of others can be very strongly reinforced when these differences are publicly evident. The presence of a united voice and of disabled persons working together at several levels can have a major impact on convincing people that the disabled do not have to be dependent upon others for their welfare.

What to note. That the constitutional aims and policy documents of the organisation are checked to see that they list the importance of working directly with disabled persons or of working with the authorities. That the organisation makes a point of disseminating its information to the local level as well as to professional workers.

Some examples. A national body might set up a support network so that persons who have been disabled for some time can work with and support families where someone is newly disabled.

Check-list

- Does the national group freely pass on its information to all levels of the organisation?
- Are records kept so that people can be put in touch with each other when they travel?

C. International links

Many exciting projects around the world provide examples at every level of what disabled persons can achieve in their communities. Passing on such examples can be vital to increasing the momentum for change. Bringing influence to bear on some of the many intergovernmental and international bodies, coupled with pressure-group campaigns from national bodies and the growing involvement of disabled persons at the local level, can convince Governments that they should support the self-help activities of disabled persons.

Representing a local group on a national body and then through it on the international body can provide an opportunity for international travel and of exchanging ideas with other disabled persons from around the world. Confidence is increased when such information is brought back and shared.

Attracting international funding for projects can also enhance the stature of national bodies and provide an impetus for a major national project. Advice and support from other organizations elsewhere can also enhance the work of national and local organizations and greatly improve the image of disabled persons.

Question to think about: When international visitors come to the country and are in touch with the national body do they also visit the local groups for an exchange of information and talks?

Some additional thoughts. A measure of the success of the networks is the amount of exchange that is encountered at the local level. Often local workers regard those involved at other levels as being out of touch or as doing things that do not influence their situation. However, work at a local level is frequently echoed by a similar scheme elsewhere. Putting people from different countries in touch can both enhance the projects by enabling people to learn from each other and shed new light on events that may be difficult to understand when looked at only in the light of the experience of one country or one locality.

What to note. Are lists of documents from other countries sent to members and made freely available to them? When people visit other countries, can they obtain the names of people and organisations to contact (does the organization keep a list of local, national and international contacts?)?

Some examples. The concern that people at a local level felt over not being able to run their own arts organization was greatly allayed when an overseas visitor was able to visit and talk about arts festivals in other regions.

Check-list

- Does the organization have links with international bodies?
- Are contact lists available for people to refer to when they visit different places?
- Does the organization encourage members to pass on information about accessible accommodation and facilities, etc., when members visit different places?

VII. LOOKING TOWARDS THE FUTURE

During the past two decades, there has been a remarkable growth of organizations set up and managed by disabled persons. It is increasingly recognized that disabled persons need to be involved in their own affairs if they are to play a full part in their communities. The traditional view that disabled persons are permanently incapacitated, waiting for medicine to provide a cure or for therapy to help integrate them into the able-bodied world where they can be cared for by professional experts, is giving way to the view that structures in society may be creating barriers to the involvement of disabled persons in society. The removal of these barriers is seen as a way of finally enabling disabled persons to play a full role in their own local communities.

A. Removing barriers

In their pursuit of well-being, human beings have made very fundamental changes to the physical world and their social relationships. Since disabled persons have largely been absent from this process, it is no wonder that while the changes have made life easier for able-bodied persons, very real barriers for disabled persons remain. Obvious ones include steps and stairs; inaccessible transport, schools and public buildings; working practices that demand high speed and intricate movements; use of auditory languages; visual information exchange; and expectations of behaviour that discriminate against those whose control over their bodies is limited. All these barriers can be labelled as disabling to persons who have specific types of impairments.

Seen from this point of view, the problem of living and managing in the community depends very much on the ability to identify correctly the barriers that disabled persons encounter and to work out ways to remove them. Medical and paramedical approaches that deal with correcting physical and mental impairments do not affect disabling barriers in the social and physical environment.

B. Developing services

Support services are aimed at assisting disabled persons to live as functioning citizens in their communities, which is different from providing services aimed at curing disabled persons (or at making them as normal as possible) or, when this is not possible, at caring for them for the rest of their lives as passive and dependent beings.

Organizations of disabled persons have spent much time discussing whether their main role should be to influence and, where needed, to change existing services provided by able-bodied persons or to start providing their own services. In practice, many groups have started setting up their own projects, which almost always aim at enabling disabled persons to integrate into their communities where they can live independently like their peers.

For example, centres for integrated living or centres for independent living are planned, set up, operated and maintained by organizations of disabled persons.

The discussion about whether disabled persons should provide their own services, or the State or private groups, is perhaps over, as so many such services are already operating or being set up. However, it is still far from clear exactly where such approaches might lead and how new organizations should regard them when preparing their constitutions and policy documents. What is clear is the desire to put much greater attention on the identification and removal of barriers and for disabled persons to be in the forefront of developing new ideas and approaches. Organizations will therefore need to play a much greater role in educational processes.

Many organizations prepare educational materials for schools and send their members to address schools. However, more books are needed that depict disability not as a personal tragedy but as a consequence of disabling barriers. Curriculum changes are also needed so that disability studies become a respected area of knowledge (like studies on women and on race).

C. Promoting research

Research on disability has mainly concentrated on the search for a cure or for the most effective way of assimilating disabled persons into the able-bodied world. This approach, however, leaves all the barriers in place and puts pressure on disabled persons as if they possessed a solution to, or were themselves, the problem.

Surveys count the numbers of disabled persons and provide evidence for Governments to plan, care or to provide pensions for an assumed inability of disabled persons to manage in an able-bodied world. There are no measures that identify the barriers that disabled persons with impairments, such as counting the number of inaccessible buses or identifying how dependent disabled persons are on receiving and giving information by sound or by visual means.

New approaches to research are, however, emerging as organizations of disabled persons realize that there is a need for hard information to inform decision-making about the removal of barriers and the setting of priorities or whether a project should focus on one area or another.

D. Becoming equal citizens

For many disabled persons and new organizations of disabled persons the main concern is to build up pressure for the barriers to be removed that prevent them from playing a full role in society as equal citizens with their peers.
