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ABSTRACT

This newsletter theme issue focuses on the Global Workshop on Children with Disabilities, which was designed to promote a multisectoral dialogue to secure and expand opportunities for children with disabilities and their families to be included on equal terms in global economic and social development. The opening statements of Stephen F. Mosle from the Academy for Educational Development, Ambassador Benny Kimberg from the Danish International Development Assistance organization, Fay Chung from UNICEF, and John Langmore from the United Nations Secretariat are summarized. Information from working groups and concurrent sessions on the following topics is summarized: (1) family involvement for children with disabilities; (2) coordinating services for economic development; (3) coordinating services for social development; (4) public awareness and information sharing; and (5) protection and rights of children with disabilities. Statements from the Commission for Social Development, a group of non-governmental organizations relating to disability, the head of the Belgian mission of Doctors Without Borders, and a representative of DA International are included. (CR)

DISABLED PERSONS BULLETIN

No. 1, 1997

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Introduction

This special issue of the Bulletin *focuses on the Global Workshop on Children with Disabilities, which was held at Washington, D.C., from 5 to 7 February 1997.*

The Bulletin *also reviews a number of other activities in the field, including the discussion of the report of the Special Rapporteur on Disability by the Commission for Social Development at its thirty-fifth session.*

Global Workshop on Children with Disabilities
(Washington D.C., 5-7 February 1997)
Background

The convening of the Global Workshop on Children with Disabilities was directly related to two resolutions recommended for Economic and Social Council adoption by the Commission for Social Development at its thirty-fifth session. In the draft resolution entitled "Equalization of opportunities for persons with disabilities", the Commission recommended that the Council note with appreciation the work accomplished by the Special Rapporteur on Disability of the Commission for Social Development, and decide to renew his mandate for a further period of three years to continue the monitoring of the implementation of the Standard Rules on Equalization of Opportunities for Persons with Disabilities. The Commission recommended that the Council call for a higher priority to be given to disability activities within the United Nations system, and urge Governments to enhance cooperation with the United Nations and non-governmental organizations to implement the World Programme of Action concerning Disabled Persons and the Standard Rules on Equalization of Opportunities for Persons with Disabilities with a view to promoting integration of persons with disabilities and social services for all. The Commission also recommended that the Council urge the Secretary-General and Governments to give full attention to a gender perspective and to the rights of children with disabilities in all policies and programmes related to disability, and request the Secretary-General to include the priority themes of social integration of disabled persons and social services for all in his reports to the Commission at its thirty-sixth and thirty-seventh sessions on relevant activities of the United Nations system.

In the draft resolution entitled "Children with disabilities" the Commission recommended that the Council note with concern that a large number of children have become disabled physically or/and mentally as a result of poverty, disease, wars and other forms of violence, and urge Governments to pay special attention to children with disabilities and to ensure that children with disabilities enjoy the highest attainable standards of physical and mental health as well as equal access to education. The Commission also recommended that the Council request the Special Rapporteur on Disability to specifically focus on children with disabilities and to establish close working relations with the Committee on the Rights of the Child, as well as to include in his report to the Commission at its thirty-eighth session his findings and recommendations on children with disabilities.

The Workshop began as a vision for expanding opportunities for children with disabilities and their families in developing countries, much as they had been expanded in the industrialized world over the past 25 years. Research revealed that that mostly invisible and at-risk population of an estimated 140 million children, 80 per cent of whom were located in rural communities, were not fully involved in global social and economic development planning or programming.

Under the leadership of the Disabilities Studies and Services Centre, a task force at the Academy for Educational Development researched and prepared a concept paper entitled "Children with disabilities: the world's promise" in February 1996. Seed money from the Dole Foundation for the Employment of People with Disabilities financed the concept paper and its use as the underpinning of discussions with donors, international nongovernmental organizations, government representatives, practitioners, parent organizations and disability advocates worldwide. Those discussions led to a partnership of organizations to sponsor the Workshop. The sponsors that provided resources to implement the Workshop and to include participants from developing countries to attend the Workshop were:

United States Department of Education, Office of Special Education and Rehabilitative Services

United Nations Children's Fund (UNICEF)

Danish International Development Assistance (DANIDA)

Department for Policy Coordination and Sustainable Development of the United Nations Secretariat

Dole Foundation for the Employment of People with Disabilities

Academy for Educational Development

Collaborating organizations which also supported participants from developing countries and technical assistance in the planning of pre-Workshop and/or Workshop sessions were:

African Development Foundation

Confederación Mexicana de Organizaciones en favor de La Persona con Discapacidad Intelectual

Disabled Peoples' International

George Washington University

Rehabilitation International

United States Department of Health and Human Services, Maternal and Child Health Bureau

World Bank

World Institute on Disability

The Planning Committee met in June 1996 to define the framework for the Workshop. The original two-day format was expanded to include two additional days of pre-Workshop training activities to be organized by several of the collaborating organizations and the Academy for Educational Development. Those activities were designed specifically for participants from developing countries to assist them in:

(a) Identifying and discussing the status and contributions of children with disabilities and their families;

(b) Sharing best practices in providing community-based, inclusive opportunities for children with disabilities and their families, and discussing how to build effective, sustainable partnerships across systems through strengthening non-governmental organizations, capacity-building and advocacy skills to meet the special needs of children with disabilities and their families.

Through a series of teleconference meetings, the Planning Committee further refined the goal of the Workshop to promoting a multisectoral dialogue in order to secure and expand opportunities for children with disabilities and their families to be included on equal terms in global economic and social development.

Opening and guest statements

Mr. Stephen F. Mosley (Academy for Educational Development)

Mr. Stephen F. Mosley, President and Chief Executive Officer of the Academy for Educational Development, opened the session with the following remarks about why such a workshop was being convened. "Children with disabilities and their families," he said, "need to be included in the schools and communities in which they live. They need to participate as fully as possible if communities and nations are to thrive. Enormous strides have been made in the last decade to improve the life chances and health of children, notably through work on child survival carried out by UNICEF under the leadership of the late Tim Grant.

"To bring about and fully achieve economic self-sufficiency along with full participation of the community, we need to assure that children with disabilities have opportunities for education and employment. Children with disabilities and their families should and must participate in — that is, contribute to — all aspects of the civic life of their communities.

"There are a number of things that have to happen to assure that children with disabilities and their families have access to education and employment opportunities. We need information and knowledge to change public attitudes and awareness; community support to coordinate services and resources; and a public policy agenda that assures both of these are present in every community.

"We have made some progress in the United States of America in the past 25 years and you will hear about some of those success stories over the next three days. In addition, there have been some outstanding success stories going on in developing countries, some of which you've already begun to share and will continue to hear about for the next three days.

"To make this a global phenomenon, it will take extraordinary collaboration and partnerships from developing and post-industrial nations, donors and practitioners, Governments and community leaders, parents and service providers, and the most important voice — that of the disability community itself. We have with us today just such a diverse and impressive group: over 25 countries are represented here today, and, within that group, there are 31 advocacy groups, including officials from seven Governments and representatives from 17 non-governmental organizations and 14 bilateral and multilateral development assistance organizations.

"The Academy's interest in this issue comes from over 25 years of development assistance in the developing world, coupled with a new and deep commitment to disabilities as seen in our Disabilities Studies and Services Centre. We are pleased to be the Convener of this Global Workshop, and over the past year have worked in close partnership and collaboration with a number of bodies,[1] all of which made a significant contribution."

Ms. Carol Valdivieso, Vice President and Director, Disabilities Studies and Services Centre, Academy for Educational Development, then introduced the four guest speakers representing the Workshop's sponsoring organizations: Ambassador Benny Kimberg (DANIDA), Ms. Fay Chung (UNICEF), Mr. John Langmore (United Nations Secretariat), and Ms. Judith E. Heumann (United States Department of Education). Each speaker addressed the theme "Why are we here? Children with disabilities and their families: reaching full participation in global economic and social development", as set out below.[2]

Ambassador Benny Kimberg (DANIDA)

"Thank you for the invitation to address this conference. Denmark, for one, is very pleased with the initiative taken by the Academy for Educational Development to convene the Global Workshop on Children with Disabilities with the overall aim of reminding all of us about the world's promise to children and their families.

"It is indeed gratifying that so many sponsors and agencies have come together to support this initiative. The participants represent a wide range of actors: non-governmental organizations and Governments from developing and industrialized countries, and international agencies. I am especially pleased to see that so many representatives from organizations of and for people with disabilities have come to this Workshop. Without their input, this Workshop would not be able to attain its goals.

"Denmark has supported this Workshop since the initiative was first brought to our attention — with funding and with participation in the planning, and by bringing to the workshop representatives from the ministries of education in Uganda and Nepal — who are our partners in DANIDA-supported programmes for children with special educational needs in the two countries. In the short period since 1989, significant declarations and documents have emphasized the rights to education and protection of children with special needs. They are:

1. The Convention on the Rights of the Child adopted by the General Assembly of the United Nations (1989). Universal ratification in 1995 (I believe only 3 countries are still outstanding).

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[1] See lists contained in background above.

[2] A copy of Ms. Heumann's statement was not available for publication.

2. The World Declaration on Education for All and Framework for Action to Meet Basic Learning Needs, adopted by the World Conference on Education for All, at Jomtien, Thailand, in 1990.

3. The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the United Nations General Assembly in December 1993.

4. The Salamanca Statement and Framework for Action on Special Needs Education, adopted by the World Conference on Special Needs Education: Access and Quality, at Salamanca, Spain, in June 1994.

5. The Copenhagen Declaration and Programme of Action adopted by the World Summit for Social Development at Copenhagen in March 1995.

"In the Convention on the Rights of the Child adopted by the United Nations in 1989, it is stated in article 23 that a child with disabilities has the right to special care, education and training to help him or her enjoy a full and decent life in dignity and achieve the greatest degree of self-reliance and social integration possible. The right to education for all children was emphasized in the World Declaration on Education for All. Those views are further underlined in the recent Salamanca Statement and Framework for Action on Special Needs Education, in which it is stated that schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions. This should include disabled and gifted children, street and working children, children from remote or nomadic populations, children from linguistic, ethnic or cultural minorities, and children from other disadvantaged or marginalized groups.

"Denmark has been actively involved both in the Education for All declaration and in the follow-up World Conference on Special Needs Education, and is now in different ways involved in implementation of the principles stated in those and other declarations concerning the education and protection of all children. Evidently, it is one thing to agree to forward-looking and progressive principles, and another thing to ensure their implementation. Often, the distance between the decision makers and the target groups at grassroots level who are expected to benefit from those principles is very far indeed, and many steps must be taken to reach them.

"I am pleased to note that in the planning of this Workshop care has been taken to involve participants not only from different parts of the world but also with different functions: donors and recipients, multilateral and bilateral donors, decision makers and people responsible for implementation, various non-governmental organizations for and of people with disabilities, donors and agencies who have already started to integrate children with disabilities and children in especially difficult circumstances in their programmes, and others who want to do so after this Workshop. Formal and informal networks and considerable exchange of experience will no doubt be one important outcome of this Workshop. As to a more focused follow-up, I understand that a meeting of the Workshop planners has been scheduled to take place right after the conclusion of the Workshop. I welcome that and hope that it will be possible to agree on a focused follow-up to the Workshop, both in the short and the longer term.

"Let me now turn to Denmark's policy for children with disabilities and their families in developing countries. In 1994, the Government of Denmark approved its strategy for Danish development policy towards the year 2000. According to this strategy, Denmark particularly focuses on combating poverty and on the most vulnerable and hardest to reach groups in each country. Certainly, children and adults with disabilities are among the poorest and most vulnerable groups in developing countries, and are therefore clearly a target group within the new strategy.

"Danish bilateral assistance in this area is now changing from support for a number of projects in a given country to programme support in more comprehensive areas or sectors in order to achieve a more significant and lasting impact on development in our partnership countries. Primary health care and education are two of the sectors given high priority in the new Danish strategy. Both sectors have direct and indirect importance for prevention of disabilities and rehabilitation of disabled children and their families. As sector programmes in health and education are being developed for our partnership countries, children with disabilities and children in especially difficult circumstances, often described as children with special needs, will become a natural, integrated part of these programmes.

"On the multilateral side, Denmark is a strong supporter of UNICEF. As a member of the Executive Board of UNICEF, Denmark in June 1996 endorsed the review of UNICEF policies and strategies on childhood protection. That paper aims to translate into active UNICEF policy the guiding principles of the Convention on the Rights of the Child for the overall protection of childhood. Let me add that it does so very successfully. In order to assist UNICEF in integrating the child protection strategy into its policies and different sector programmes at headquarters, regional and country levels, Denmark has decided to offer increased technical and other assistance by providing a senior expert in childhood disability to UNICEF.

"As for Denmark's own experience in this area, Denmark has a long tradition of taking care of its citizens, not least the particularly vulnerable ones. Our health care, social and educational systems include all citizens, including people with disabilities. We have spent a long time in developing our welfare society. Although Danish people often complain about their high taxes, there is general agreement that we want to maintain a society where there is room for everyone and where everyone is entitled to needed help and support. Naturally, this system is not without problems, and adjustments must be made according to changing needs and conditions, but there is now in the Danish population an almost general agreement that not only can we afford but we also feel obliged to help people and countries in other parts of the world, not only with technical development but in the areas of human development as well.

"Danish development assistance to developing countries has always included the health and medical areas. We have now provided support to education in different projects in many countries as well as individual special education projects. Recently, Denmark started supporting education and rehabilitation projects for children with special needs in some countries of the former USSR. Over the last 10 to 15 years, DANIDA has supported the development of special education programmes in Kenya, Uganda, Nepal and Mongolia, in collaboration with their respective governments. Special education is being developed as an integrated part of the existing education system. The four programmes are based on the different circumstances and needs in each country and are therefore not identical in their structure, but over the years a number of lessons have been learned, some good and some not so good. Changes have been made and broader, more comprehensive target groups have been included, such as children with special needs (0 to 18 years).

"Denmark is among the countries with most experience in developing special needs education programmes in developing countries. Often, Denmark finds itself the only donor of a special needs education programme, but we are ready to collaborate with other donors and to share our experiences with any donor or agency that wants to share our experiences.

"Improvement of basic and primary education is becoming a priority area of Danish assistance to developing countries. Special needs education is seen as an integral part of this. Children with special needs (0 to 18 years) include children with disabilities and learning difficulties, children in especially difficult circumstances and children at risk in accordance with the Salamanca and other international declarations. Early identification and intervention are seen as a part of all the programmes.

"The DANIDA approach to special needs education is defined as programme support for development. The intention is that the programme will set in motion a number of processes that can be continued and sustained after DANIDA support ends. The aim is to develop a nationwide coverage for special education as part of the regular education system. DANIDA recognizes that development of a national special needs education system as part of the regular education system will take a long time, and therefore plans support to special needs education programmes over a long time period, possibly 10 to 15 years.

"All DANIDA-supported special needs education programmes emphasize that children with special needs should be taught together with their peers in regular classes or schools within their regular education system. The concept of "inclusive schools", where all children are accepted and kept in the local school and promoted with their peers, is still very new to administration, headmasters and teachers in the ordinary schools in developing countries, as it is in many industrialized countries. However, it is being recognized that this is the only model that will be able to reach the majority of children with special needs. The participants from Nepal and Uganda who are our partners can, of course, describe in much more detail our joint efforts to include children with special education needs in mainstream education in the two countries. Our consultant can also tell you about experiences from Kenya and Mongolia.

"One of the most crucial factors in development of special needs education programmes in any country is the availability of professional expertise. Therefore, one of the main components in the programmes is technical capacity-building, ranging from general awareness-raising to training of teacher trainers and researchers at university or special education institute levels. Continued in-service and upgrading training of teachers is one important key to sustaining quality in such programmes.

"Availability of specially prepared, professionally sound and appropriate materials is a key element in development of a special needs education programme. Such materials are both needed as part of technical capacity-building and for children with special needs. This is one of the lessons learned by DANIDA, and materials development has now become a focal point.

"Collaboration with national and international non-governmental organizations is seen as an important element in assisting the development of sustainable programmes. This can be done in a variety of ways. DANIDA itself has increased its support to people with disabilities through cooperation with the Danish Council of Organizations of Disabled Persons, supporting a special adviser who assists the Council in identifying areas where Danish organizations can provide expertise and support to disabled people in developing countries. This programme has proved to be very effective. An interesting model for cooperation with non-governmental organizations is being tried in Nepal, where DANIDA supports a three-year project for the deaf and hearing-impaired persons, carried out by the Danish Association of the Hearing-Impaired through the Nepal Association for the Deaf, together with other non-governmental organizations. There is close cooperation between this project and the special needs education programme, whose leaders are participating in this Workshop. No special needs education programme can be successful without the support of parents. If parents do not understand and therefore do not support the special needs programme, it is not likely to succeed. Involvement and education of parents should be directed not only at the parents of children with disabilities but at the parents of all children in a school to increase their understanding, overcome resistance and gain their support for the programme. Therefore, cooperation with parents and the community is a central part of the special needs education programmes.

"Let me conclude by referring to a special DANIDA publication on the Education Assessment and Resource Services (EARS) programme in Kenya for the Rehabilitation International conference in 1992, entitled, "Afford it? But of course!" The question is still asked frequently from many sides: Why help children and adults with disabilities when so many non-disabled also need support? The Danish answer is still "but of course". Gradually, more developing countries are realizing that they cannot afford not to help children with special needs and their families to be part of the global and social development. With early identification of special needs and appropriate intervention and support, the majority of children with special needs will become useful and independent citizens in the society and be able to live a productive and independent life. This is their right, our responsibility and the world's promise."

Ms. Fay Chung (UNICEF)

"In the past few decades, the United Nations has adopted a number of international human rights instruments applicable to children, including children with disabilities. Among these is the legally binding Convention on the Rights of the Child (1989), now ratified by 188 countries. Article 23 specifically calls on States Parties to recognize the special educational, training, health care, rehabilitation, recreation and employment needs of children with mental or physical disabilities. Other instruments of a non-binding nature are the World Declaration and Plan of Action for the World Summit for Children (1990), the World Declaration on Education for All (1990) and the International Special Education Conference in Salamanca (1994). During 1996, as the Organization marked its fiftieth anniversary, UNICEF has taken a number of important steps to renew its commitment for the overall protection of children.

"UNICEF has formulated its Mission Statement, which was adopted by the Executive Board on 22 January 1996. The Mission Statement affirms that UNICEF is committed to ensuring special protection for the most disadvantaged children — children who are victims of war, disasters, extreme poverty, all forms of violence and exploitation and those with disabilities. In the light of the standards of the Convention on the Rights of the Child and its Mission Statement, UNICEF has reviewed its policies and strategies on child protection. In June 1996, the Executive Board adopted a new policy entitled "Children in need of special protection measures". It is in line with this commitment that UNICEF is participating in this Global Workshop with a view to improving the situation of some of the most neglected children in developing countries, those with disabilities. These children suffer from the double disadvantages of underdevelopment combined with the lack of suitable provision for their educational needs, and lack of access to rehabilitation, and play and recreational activities. Basic education is an inalienable right of every child. Today, large numbers of children with disabilities do not enjoy this basic human right, and UNICEF reiterates its commitment to support the attainment of education for all children as a major global goal.

"Prevention of disability is among the highest priorities for UNICEF programmes. UNICEF remains committed to the reduction of child and maternal mortality and morbidity through poverty reduction, universal immunization, reduction of malnutrition and elimination of micronutrient deficiencies, and access to basic education. Many disabilities are caused by malnutrition and micronutrient deficiencies. Through UNICEF nutrition and parenting education programmes, parents are educated to ensure that they prevent disabilities among children and women during the critical pregnancy period. UNICEF believes that prevention should be the first line of action, because many disabilities are preventable.

"For the world's estimated 150 million children who are already affected by disabilities due to a variety of preventable causes ranging from disease, malnutrition, natural and man-made disasters, armed conflicts and landmines, UNICEF calls for a policy of community-based prevention and rehabilitation, early detection of impairments, and timely intervention to prevent progression to disability and handicap. The policy also calls for facilities and amenities to be designed so as to include children with disabilities. Children with disabilities should be included in ordinary schools, wherever possible. The development of low-cost and durable prosthetics is needed.

"In the course of this Workshop you will hear about a number of UNICEF-supported programmes in Asia, Latin America and Africa. Mali and Ghana provide good examples of partnership collaboration. Nepal and China provide examples of community-based approaches that are well worth examining. Two good models of national community-based rehabilitation (CBR) programmes with working mechanisms for capacity-building and training are under way in Indonesia and Sri Lanka. Indonesia also offers excellent models for assessment and early identification of disability among young children. Jordan, Oman, Egypt and Zambia have developed CBR models and training materials for community workers in collaboration with UNICEF. In Belize, through an initiative of the Ministry of Education supported by the United Nations Educational Scientific and Cultural Organization (UNESCO), UNICEF is facilitating reintegration and mainstreaming of children with disabilities in the local schools. Teaching modules are designed to meet the special needs of children with learning disabilities. In Jamaica, the education programme has been redesigned to improve quality and expand coverage of children, with special attention to the education of children with disabilities in pre-schools and primary schools. UNICEF Romania is facilitating capacity-building and training through experience exchange and participation in international seminars. In Namibia, a joint initiative of UNICEF, the World Health Organization (WHO), UNESCO and the International Labour Organization (ILO) has begun to create awareness among different ministries and develop guidelines for expanded collaboration. Assistance to strengthen organizations of parents has been provided in Central America. In Nicaragua, parents of children with disabilities were organized to create awareness in the community for education of children with disabilities.

"Problems and solutions in dealing with landmines and landmine injuries come from Afghanistan, Angola, Bosnia and Herzegovina, Cambodia, El Salvador and Mozambique. UNICEF has emphasized the need to ban landmines. Landmine awareness, education and landmine clearance programmes have been carried out in countries affected by armed conflict. In addition, UNICEF has also developed closer collaboration with organizations concerned with prosthetics and orthotics for children with disabilities.

"UNICEF knows from experience that it is essential to work in partnership with other agencies if any degree of success is to be achieved. It is important that this Workshop has brought together such partners as the World Bank, DANIDA, United Nations Agencies, the African Development Foundation, private foundations, non-governmental organizations and academic institutions. It has also brought together key players from the industrialized as well as the developing world. This provides an opportunity to consolidate a partnership for action where parents and members of the community take their place alongside governmental agencies and potential donors.

"In conclusion, we hope that the Workshop will ensure that its recommendations are practical and realistic. Strategies that are adopted need to be simple, innovative, cost-effective and community-based. We want to place even greater emphasis on preventive measures, early identification and early intervention, with full parental participation and active support from the community. This is a challenge that we can and must meet as we move closer to the twenty-first century. Our experience over the past 50 years has proven to us that sustainable progress is achievable, given political commitment, adequate resources and community mobilization. In addition, the underlying causes must be analysed and sound policies and programmes formulated and implemented. Our resolutions must be achievable, and must be time-bound and measurable so that we go beyond the stage of wishful thinking and move into the stage of practical implementation."

Mr. John Langmore (United Nations Secretariat)

"The Division for Social Policy and Development of the United Nations Secretariat is very glad to have this opportunity to participate in the organization of the Workshop with the Academy and with our UNICEF colleagues. The question of children with disabilities is a major area of concern in the World Programme of Action concerning Disabled Persons and a number of other international instruments as well. The Division is also glad to be taking part in this important technical exchange and dialogue. This will not only improve our own work but contribute to strengthened and expanded networks among interested constituencies for children with disabilities.

"My statement is in three parts. I would, first, like to review and comment briefly on the international instruments which provide a basic framework for the design of strategies, policies and programmes in the field of disability. I would, second, like to provide a brief introduction to the activities of the Division concerning global disabilities policies and programmes. And I would, third, like to share with Workshop participants certain lessons that the Division has learned in the field of disability policies and programmes.

"United Nations concern with issues related to disability is rooted in its founding principles. The Preamble to the Charter of the United Nations reaffirms the faith of the international community in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women, and in the promotion of social progress and better standards of life in larger freedom.

"The Universal Declaration of Human Rights, adopted by the United Nations General Assembly in 1948, has provided a philosophical basis for the development of legislation concerning disabled persons. The Declaration states that all are equal before the law and are entitled without any discrimination to equal protection of the law. Article 25 of the Declaration recognizes that everyone has the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

"The International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, together with the Universal Declaration, provide the foundation for equal treatment and protection of persons with disabilities to exercise their civil, political, social and cultural rights on equal terms with nondisabled persons. In 1989, international protection of the rights of children culminated in adoption of the Convention on the Rights of the Child, which promotes the best interest of the child (article 3(1)).

"The United Nations has accorded special attention to the question of the rights of disabled children, which is reflected in recent declarations and guidelines adopted by the General Assembly to promote the rights of persons with disabilities. The World Programme of Action concerning Disabled Persons was adopted by the United Nations General Assembly in December 1982. The Programme of Action has as its basic goal full participation and equality of persons with disabilities. It contains a declaration of principles, sets forth policy options and outlines a long-term plan to enhance disability prevention, rehabilitation and equalization of opportunities of disabled persons to further their full and effective participation in development at all levels—national, regional and global. The guidelines for action elaborated in the World Programme focus on the importance of approaching disability issues from a human rights perspective and of incorporating these issues into the development mainstream.

"The Standard Rules on Equalization of Opportunities for Persons with Disabilities seek to provide guidelines for efforts by Governments to further opportunities for equal participation of persons with disabilities in all aspects of society. The 22 rules, listed in the annex to General Assembly resolution 48/96, represent practical tools to improve the quality of life, livelihood and well-being of persons with disability, and focus on removal of barriers to their full and effective participation in social and economic development.

"The World Summit for Social Development reflects the commitment of the international community to the principle of people-centred development, which also means a children-centred and children with disabilities-centred process of development. The World Summit for Social Development, in adopting the Copenhagen Declaration and Programme of Action, reiterated the principle of people-centred development for achieving the goals of social development. Focusing on the most vulnerable in special and difficult circumstances, the Summit was instrumental in putting the Child's Perspective, as defined in the Convention of the Rights of the Child, into the context of social development. The Summit urged the international community to (1) protect children with disabilities from the negative impact of various political, social and economic problems and (2) ensure that children's basic and special needs be met through setting essential policies and enforcing mechanisms in place in order that physical and social barriers that prevent children with disabilities from fully participating in social development be removed.

"After this brief review of the international instruments relating to disability, it is fair to ask how the Division relates to the scheme of things, what it does and what its priorities are. As focal point in the United Nations system on disability, the Division organizes its work with reference to four principal clusters of activities.

"First is the critical importance of an appropriate policy framework for supporting effective planning and programming in the field of disability. Policy content reflects relative priority. Since child disability is a cross-sectoral issue, policy guidelines provide a framework for consultation and cooperation across organizational boundaries. For this reason, the Division attaches priority in its work to supporting intergovernmental policy processes.

"Second is the need for a multi-level institutional framework that effectively links consultation and coordination of policy and planning-level decisions, for action at programme budgeting and administrative levels and for programme implementation among civil society. Policies and plans obtain content through current and reliable data, in which informed and empowered beneficiaries can make essential contributions. Policy development and plan implementation depend upon resources available, which would presuppose an appropriate fit between needs, priorities and resource capacities. The voluntary fund has supported a number of national and subregional workshops on national disability committees, and the Division has produced technical guidelines on the question.

"Third is the issue of conservation of resources to ensure sustained programme implementation. Our experience suggests that the way in which resources are organized and delivered is as important to programme implementation as is the nature of those resources. The Division has found that making programme and project agents — both governmental and nongovernmental — responsible for the seed-money grants from the voluntary fund can result in significant and multiplier effects for programme implementation and impact among intended beneficiaries. Grants from the voluntary fund have recently yielded on average five times as many resources for action in the disability field.

"Fourth is an essential need to inform and engage civil society concerning issues and trends in the field of disability, which has implications for both outreach and networking among interested constituencies. It also suggests a need to document and disseminate widely the lessons of these experiences.

"As the international community has launched a new commitment to social development in its efforts to create a just and equitable society for all, guided by the principles of the Charter of the United Nations and by international agreements reached at recent international conferences, especially the World Summit for Social Development, the Fourth World Conference for Women and the World Summit for Children, a new era of international partnerships that places needs, rights and aspirations of people, including children with disabilities, at the centre of our decisions has begun.

"Our Workshop today represents an important part of that process of renewal of commitment to create a society for all, and a determination to place children with disabilities at the centre of our efforts. Let us continue our efforts to remove the physical and social barriers that prevent children with disabilities from participating fully in social life and development."

Working Group sessions

Participants were assigned to Working Groups I to V, each with a multisectoral representation, to foster dialogue on specific questions posed by the facilitator. Each group was reminded of the overall workshop goal: to promote a multisectoral dialogue in order to secure and expand opportunities for children with disabilities and their families to be included on equal terms in global, economic and social development.

Working Group I. Family involvement for children with disabilities

Working Group I identified several resources that it felt families need to overcome obstacles and become equal participants in their nations' social and economic development. First, information — getting it, sharing it and using it — was identified as crucial to families. Group I viewed information as power and having it as enabling families to articulate better their needs and those of their children with disabilities. Several kinds of information were identified, about (a) one's child, (b) his/her rights as a human being and citizen, (c) policies and laws that affect people with disabilities, (d) research and best practices/models, (e) resources available to families, (f) other children and families like one's own, and (g) knowledge of the disability-rights movement.

Second, the group listed specific supports to families, giving them the local, positive strength they need to be advocates for their children and themselves. These included:

(a) Recognition of families as experts — acknowledgement of their natural and cultural strengths;

(b) Networking opportunities;

(c) Peer support — creating community-based support groups;

(d) Modelling by adults with disabilities for children with special needs and their families;

(e) Specific resources and concrete information needed to help raise their child with a disability, at home or in the community.

Another resource acknowledged was organizational skills, such as concepts and practices for parents/ families that encourage the formation and development of family associations at all levels (community, State, regional and national). Finally, the group stressed the need for families to be viewed as experts and partners. In a large number of arenas — policy, medical, social and educational — families need help in becoming viewed as informed decision makers along with professionals and politicians. Families need to be accepted as equal partners, working with professionals and politicians to improve opportunities for their children with disabilities.

Strategies recommended to make disability issues a consistent part of national and international development agendas were:

(a) Press nations and organizations to implement the Standard Rules;

(b) Use the media and other information mechanisms to alter the attitudes of

- (i) Professionals and politicians — those in power in social and economic arenas;
- (ii) Families themselves, helping them to see that they have the right and strength to be the centrepiece of action and advocacy for their children;
- (iii) Societies, so that they recognize both the rights and potential of children with disabilities.

(c) Change the policies of nations and organizations: mandates, laws and programme guides that are the framework within which decisions about allocation of social and economic resources are made must be altered to include equal opportunities for children and families with special needs.

As a result of these strategies, specific actions which need to be taken to affect decision-making were:

(a) Develop partnerships within nations — forge them with natural support groups, other families, the disabled community, professionals, policy makers and implementers, and other nations;

(b) Get a seat at each nation's political table — accomplish this through:

- (i) Leadership and advocacy training;
- (ii) Recognizing that families have the right to participate in decision-making affecting their children;
- (iii) Putting families on consulting boards at all levels;
- (iv) Having family members run for public office and become part of the power structure;
- (v) Requiring donor organizations to make sure family perspective is included in the funding request process, and that families will remain as partners in project implementation phase.

In summary, the group suggested that others:

(a) Recognize the unique expertise that families bring;

(b) Invest in empowering families to be effective advocates for their children;

(c) Acknowledge that no success can be achieved in meeting needs of children with disabilities without a role for families;

(d) Promote the development of grass-roots leaders to help other families;

(e) Acknowledge that families are a natural support system to other families — develop opportunities for them to network, learn from one another;

(f) Acknowledge that families must be involved at all levels of decision-making and of implementation about programmes for their children.

Working Group II. Coordinating services for economic development

Mr. Sulemana Abudulai (Ghana Action on Disability in Development) served as Rapporteur and began by noting the Working Group's composition: seven non-governmental organizations in Asia, Africa, Europe and the United States; six government ministries or departments, and universities; two international disability organizations; and six donor agencies. He then described the barriers and challenges facing disabled persons that the Working Group had identified:

(a) Social barriers, including religious attitudes, which fragment communities are further promoted by donor focus — disability, gender, religion;

(b) Emotional barriers — disabilities are not part of everyday life, invisibility breeds low self-esteem;

(c) The gap between national policies and local realities — ranging from difficulties in implementing legislation to building trust at all levels, truly sharing responsibility for disabled persons.

(d) "Navel gazing" — cooperation among donor agencies, Governments and advocacy groups is eventually stifled by inward-looking organizations;

(e) Inertia — it takes energy to move from the status quo;

(f) Inappropriately trying to place Western models into non-Western areas — square peg in a round hole syndrome;

(g) Outcome-oriented curricula and programmes — need for coordination with labour, business, employment needs of the community as school/training programmes are being developed;

(h) Fickle interests of donors — tend to support "hot" topics, constantly changing focus, resulting in a lack of continuity;

(i) Failure to recognize and use community resources — donor community needs to recognize existing strengths of the local community and to build the capacity of the local community in order to insure programme sustainability.

The Rapporteur noted that the discussion reflected introspection on the part of the various sectors represented in the room. For example, in many cases these comments were brought up by the very representative whose group was being criticized.

The Working Group began by considering the current view of service delivery, which sees agency resources at the centre, with channels for services to be delivered out to individuals and groups in the community. However, the Working Group abandoned this model in favour of one that placed the child at the centre, surrounded by resource agencies, non-governmental organizations, community-based groups, all linked in a system that fostered their continuous collaboration.

The Working Group discussed and presented several ideas for how to move beyond these obstacles. They suggested that:

(a) Donors focus on building the capacity of communities and local and government officials to meet their needs, develop policies and sustain programmes;

(b) All sectors form cells of partners in each community;

(c) Donors and community representatives decide jointly on projects;

(d) Annual meetings of area donor organizations be conducted;

(e) Content-specific workshops at both the country and local levels of all stakeholders (non-governmental organizations, family groups, disability organizations, government agencies) be conducted;

(f) Programmes be developed to offer help and support to the siblings of children with disabilities, as well as the children of disabled people;

(g) Networking among grass-roots level groups — voices from the people — be promoted;

(h) Donor groups stimulate/train localities to recognize their own needs and to develop plans to request support for these needs;

(i) Donors train government-level personnel to appreciate information and requests from the local level and respond to grass-roots needs;

(j) Facilitate non-governmental organizations and Governments together, sponsoring workshops around certain themes so proposals can be developed;

(k) Donors facilitate Governments in holding national and local conferences on children with disabilities, and invite all groups to attend, i.e., groups in the areas of transportation, health, labour, women's groups and education;

(l) Donor education seminars be held in countries for donors working in that country;

(m) Donors collaborate to meet needs identified in the country;

(n) Documentation of needs be developed, including training to appreciate the importance of accurate data, research needs, regional information/resource centres and a hierarchy of information needs.

The Rapporteur concluded by stating that the Working Group was willing to make a series of commitments in response to the question, "What do you commit to change when you return to your country?" The commitments included:

(a) Networking regionally to continue steps begun here to share and help each other;

(b) Strengthen voices of parents;

(c) Facilitate the formation of parent associations.

Working Group III. Coordinating services for social development

The Working Group rapporteur, Penny Platt (University of Manchester), explained that one of a series of questions considered by the Working Group in its discussions was "How will we know when disability issues are squarely on the agenda for social development?" Two frank responses were: "When the Executive Director of UNICEF attends this conference" and "when in my country, disabled people have a life like the others". These two responses lead to the Working Group's goal(s) of achieving full, equal recognition, and value of people with disabilities.

What suggestions did the Working Group make for achieving these goals? The two key words underpinning every idea and central to every level of initiative were collaboration and cooperation:

(a) On raising awareness of the rights and needs of disabled people throughout society;

(b) On supporting the capacity-building of disabled peoples' organizations;

(c) Between organizations of people with disabilities, parents and professionals (and recognizing the inclusion in many regions of parents within organizations of disabled people).

Given these strategies, the Working Group considered ways to bring about this level of collaboration:

(a) Conferences as wide-ranging as this one should be held within recipient countries, thus facilitating both intra-country and pan-regional development;

(b) Nationally, it is useful to create an umbrella organization of interested organizations;

(c) Parents of children with disabilities need encouragement and resources to work together to support each other and disabled persons;

(d) Organizations of disabled persons need to reach and support disabled people not only in towns but also in rural areas (where it is estimated that 80 per cent of them live);

(e) Professionals need disability awareness training on the issues, the importance of reciprocity, and in preparation for service implementation;

(f) Disabled children should have the expectation and training to provide them with work in adult life, and Governments should be supportive of efforts to achieve this;

(g) Adolescents should have their own organizations reflecting their needs, such as theYoung People First organizations in the United Kingdom;

(h) Organizations should join forces to advocate for disability rights within any and every discussion of child/human rights;

(i) Strengthen coordination and communication among organizations and countries, as well as among United Nations agencies;

(j) Establish an interministerial committee/coordinating body to exert pressure on the respective ministries involved with disability issues within a given country; and, better still, a goal still to be achieved in most countries, every ministry should hold a briefing to act on disability issues which fall within its jurisdiction.

If the above is achieved, it will promote the three key building blocks: (a) training, based on (b) information exchange and (c) experience exchange. But only when we are all understanding together, when we are with disabled persons and not merely for disabled persons, can we start to really, effectively and seriously bring disability equality into social development.

The Rapporteur contributed her personal perspective to summarize, including children with disabilities in community resource allocation and social development, using her own descriptors for "CHILD":

> Collaboration, cooperation, communication and coordination;
>
> Health and education need to work closely;
>
> Include disability issues in every Ministry;
>
> Life is of equal value, no matter whose it is;
>
> Disability, a dimension to every dialogue.

The Rapporteur remarked that within the Working Group there was evidence of a willingness to begin to make commitments to next steps (reported above). However, time did not permit the entire Working Group to discuss these thoroughly and make them part of its presentation to the final general session.

Working Group IV. Public awareness and information sharing

During both the pre-Workshop activities and the concurrent presentations, participants from developing countries made clear that they were in search of technical information and financial support. They noted that the Western participants seemingly had little idea of the circumstances facing agencies for disabled children in developing nations. Therefore, this Working Group began with an exercise that enabled representatives from India, Uganda, El Salvador, Cambodia and Mexico to present in their own terms the home country situations they face.

Throughout its discussions, the Working Group tried to balance the need for external resources, such as financial aid and technical assistance, with the need to maintain a sense of local control over the direction of development efforts. This seems to be key to creating a genuine partnership among community-based, national and international assistance leadership.

The most significant obstacle identified was social attitudes. Deeply rooted cultural beliefs, which often stigmatize and devalue disabled children, were faced daily at both the community and family levels. As rapporteur Edward Kimuli (Uganda National Institute of Special Education) described them, there were five roots of perceptions of low value of disabled children discussed by the group: (a) lack of exposure to disabled children, (b) stigma, (c) religion, (d) lack of information, and (e) cultural beliefs. In one developing country, disability was frequently blamed on the violation of food taboos during pregnancy; in another, parents' attitudes towards a disabled child depended upon the coincidence of the birth with spiritually significant events. "Remedies" for the disability could involve the child in an intensive and potentially harmful regimen of folk medicine and ritual.

The Working Group felt that interventions, whether through public awareness campaigns or education focus groups, required enormous sensitivity to these deeply rooted cultural beliefs in order to be effective in changing local perceptions about disability. They agreed that attitudes towards children with disabilities were grounded in specific and complex circumstances of culture. Changing social attitudes and awareness towards disabled children would, therefore, call for careful reflection and understanding of the particular conditions in a given society.

Another obstacle was the lack of motivation on the part of national Governments to implement the Standard Rules, to take a leadership role in incorporating disability issues into sectoral development and to commit resources to support them.

Among the prerequisites for developing strategies to alter social awareness and attitudes towards children with disabilities was the need to define (a) the problem to be addressed, (b) the group or social level to be targeted, (c) the "message," and (d) the organizational vehicle by which it could be most economically delivered. The strategies to increase public awareness of the value of children with disabilities and to build self-confidence were:

(a) Support popular education through cinema and street theatre;

(b) Increase the visibility of people with disabilities — as role model, advocates and experts on disability issues;

(c) Promote association of children with and without disabilities — create opportunities for them to work, study and play together;

(d) Encourage cross-disability interaction and joint ventures to build momentum for advocacy;

(e) Link parents of disabled children with organizations of disabled people — create alliances;

(f) Make changes in the law.

Each of these strategies, in order to be more effective, required specifically designed forms of organization and funding. For example, the success of linking parents with disability groups would depend on the presence in a nation/community of both strong organizations of parents and groups of disabled adults. In addition to calling for leadership training, the group suggested that one strong organization act as an umbrella to the others, take the lead in initiating a project, securing funding and bringing parents and disabled people together.

For this Working Group, changing perceptions of value held towards children with disabilities required collaboration among influential social institutions, both at the national and international levels. It was emphasized that national Governments are expected to initiate and monitor the effort, as stated in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. This doctrine also described awareness-raising as a precondition for equal participation. National Governments must be centrally involved so that there is timely response to the great demand for services that inevitably follows a successful awareness campaign.

In any case, the Working Group concluded that the essential problem remained: motivating national Governments to address the concerns of disabled children and to incorporate disability issues into sectoral development. The international community was viewed as playing an important role by setting positive examples and monitoring standards. However, economic realities and cultural belief patterns weighed heavily; and changes in perceptions must be accepted as a slow process. One international donor commented that many issues were not manageable from afar, and that some donor Governments suffered from fear of failure in the arena of social assistance and equity. The Working Group suggested, therefore, that: (a) awareness-raising campaigns be conducted at every level, from the national level down, as well as from the family/local level up; and (b) technical cooperation between developing nations be started, because similar conditions would make for more applicable and relevant assistance.

Although non-governmental organizations were often more attuned to the needs of children with disabilities and their families, they compete for scarce resources. Funding requirements that encourage coordinated efforts were suggested as helpful in fostering partnerships of non-governmental organizations and community-based organizations, as well as maximizing limited resources. While the Working Group encouraged cross-disability efforts that they thought might be more influential and politically successful, it recognized that real, irreducible differences in needs and perspectives exist between different groups of disabled people. More information about one another could only result in more opportunities to explore common ground and get those issues onto the development agenda. With few donor representatives participating in these discussions, the Working Group felt it lacked the expertise to knowledgeably address the topic of actually getting the issues of children with disabilities and their families onto the international agenda of development assistance.

First among the next steps to be taken within each country was the full implementation of the Standard Rules. Both non-governmental and state agencies should be queried about conditions for disabled people.

Second, the Working Group agreed to network with one another for the purpose of sharing information about methodology in programmes for children with disabilities. Many participants provided referrals about sources of funding and information resources in other areas of disability.

Getting access to the Internet was deemed a key aim of those participants not currently on line, since information of various sorts is rapidly and freely available. For many, the Internet also held the potential for continuous networking of expertise and contacts made during the Workshop.

Finally, the "waiting task," as it was described, remained figuring out a satisfactory way to combine local control over the direction of development efforts with assistance from the international community.

Working Group V. Protection and rights of children with disabilities

Serving as rapporteur, Charlotte McClain (Community Law Center) synthesized the Working Group's underlying concerns into two goals/themes: (a) bolstering agencies/divisions in their commitment to compliance of Standard Rules on Equalization of Opportunities for Persons with Disabilities at the country level, especially in ensuring inclusive planning and programming, as well as regular review of both; and (b) encouraging donors to devote a percentage of funding to the further realization of real promotion of disability issues along with human rights, i.e., making this one of the criteria for development.

To accomplish these goals, the Working Group suggested several concrete strategies, each with the objective of providing (a) an information strategy to educate key personnel, and (b) the promotion of partnership at all levels — community, national, regional and global. Their framework for action called for a fundamental shift to a rights perspective, rather than a charity perspective. The steps to achieve this shift were identified as:

(a) Promote recognition through legislation, planning and information;

(b) Develop or enhance mechanisms for reporting, enforcing, utilization and timing of programmes for children with disabilities and their families;

(c) Political and legal action including (i) oversight and advocacy, (ii) Department of Peacekeeping Operations of the United Nations Secretariat/non-governmental organizations support, (iii) international exchange, (iv) accountability and (v) transparency;

(d) Strengthen and create inclusivity by focusing on parents, community groups, and the poorest of the poor.

The Rapporteur then described several activities and outcomes that the Working Group proposed as a means for fostering the paradigm shift:

(a) Identify and examine country reports for inclusivity on disability issues;

(b) Organizations review plans for action, documents, data related to the "rights" focus;

(c) Review of disability-adjusted life years;

(d) World Bank "indicator";

(e) International disability/rights consultant to identify resources, organizations and model programmes involved in rights of children with disabilities, for example, through such regional bodies as ASEAN, SAARC, OAU and ESCAP;

(f) Workshops, advocacy, media — increased public awareness;

(g) Inclusivity of human rights in all social and economic development planning;

(h) Baseline for data;

(i) Accountability;

(j) Regional and national capacity-building.

The discussions of the Working Group emphasized the following five action steps to ensure that the protection and rights of children with disabilities remain addressed by every sector and are integrated into development thinking:

(a) Promote the recognition of human rights by:

    (i) Adopting comprehensive legislation;

    (ii) Incorporating human rights into all levels of policy and planning;

    (iii) Providing appropriate and accessible public information and education;

(b) Develop and enhance international mechanisms for reports, their enforceability, utilization and timing;

(c) Ensure political and legal action for domestic enforcement through:

    (i) Oversight and advocacy;

    (ii) Department of Peacekeeping Operations of the United Nations Secretariat/non-governmental organizations support;

    (iii) International exchanges for capacity-building;

    (iv) Accountability and transparency;

(d) Strengthen and create inclusivity within national planning and advocacy groups (parents of children with disabilities, community groups, poorest of the poor), resulting in:

    (i) Empowering families;

    (ii) Providing family support;

    (iii) Ensuring quality of access;

(e) Facilitate a paradigm shift from a "charity perspective" to a "rights perspective" in programming, planning and delivery of services.

Concurrent sessions

Four concurrent sessions, each repeated in its entirety so that Workshop participants could have the opportunity to attend more than one session, focused on "Family involvement for children with disabilities", "Coordinating education and health programmes", "Public awareness and information sharing" and "Protection and rights of children with disabilities".

The concurrent sessions were designed to provide Workshop participants with exposure to programmes and practices currently under way in developing countries. They illustrated ways that Governments, communities and individuals create opportunities for children with disabilities and their families through economic and social development policies and programmes.

Family involvement for children with disabilities

Suzanne Reier (World Institute on Disabilities) began her introductions by emphasizing the importance of family involvement. "The family", she stated, "is the first and most enduring point of contact for children with disabilities." Ms. Reier then introduced the first two presenters: Roberto Leal Ocampo (Confederation of Central American Parent Associations of Children with Disabilities) and Diane Richler (Canadian Association for Community Living). Ms. Reier remarked upon the wide variety of experience Mr. Leal has had, ranging from serving as Nicaraguan Ambassador to several Central American countries to being the founder and director of an association of family and parent organizations. She described Ms. Richler's involvement with and commitment to inclusive education and living for people with disabilities. Finally, she indicated that Mr. Leal and Ms. Richler had prepared their presentation collaboratively, and that Ms. Richler would speak on behalf of both of them.

Ms. Richler began by stating that she and Mr. Leal had been working in collaboration for many years, and that she would be talking about their three-year project, Partnerships in Community Living, which began in 1993 and ran through 1996. Funded by Canada, the project was intended to promote social policy and forge alliances to help families and children with disabilities. The project was conducted on a hemispheric basis, and drew together representatives from 36 countries for a seminar at Managua, Nicaragua, in 1993. Each country sent three representatives: one parent of a child with a disability; one professional who worked with individuals with disabilities; and one government representative. Interestingly, many of these representatives did not know one another, even though they were from the same country. The project was based on the concept that families need to be present at all stages of planning and implementation of social policy. "The role of parents is fundamental", said Ms. Richler, "because of their ongoing, lifelong commitment to their sons and daughters. Professionals, no matter how much they care, come and go, but the parents remain."

The guiding framework of the Managua seminar and of the project thereafter was a clear endorsement of a human rights perspective on disability. There had never been a grouping of people like this before. Was there a common vision for people with disabilities in the hemisphere? Yes. "Once you stripped away language, economic situations and differences of culture, the vision was very uniform", Ms. Richler said. "It was based on the broad concept of human rights." The five-day seminar culminated in the Declaration of Managua, which was signed on the last day in the presence of the President of Nicaragua. Ms. Richler read the opening paragraph of the Declaration, which, she said, encapsulates the vision that has guided all their work:

> "To ensure social well-being for all people, societies have to be based on justice, equality, equity, inclusion and interdependence, and to recognize and accept diversity. Societies must also consider their members, above all, as persons, and assure their dignity, rights, self-determination, full access to social resources and the opportunity to contribute to community life."

She pointed out that nowhere in this Declaration is there mention of disability. Participants in the seminar believed that it would be impossible to build an inclusive society if special rights were given to those with disability. "In order for us to be able to think about communities where children with disabilities could fully exercise their rights, communities had to be inclusive of everyone. If we were looking to build only disability rights, it meant that others would be excluded. So a human rights perspective was taken."

One of the major findings of the project: While individual nations can do a lot to improve conditions and circumstances for people with disabilities, their work and social policy can be adversely affected by activities of organizations beyond their borders. Example: An international financial institution decides to emphasize projects focused upon educating girl children. In funding such activities, the institution unintentionally creates a system that does not take into account children with disabilities, and in fact limits their opportunities by emphasizing opportunities for another.

The project has identified a number of international funding organizations, and has been encouraging them to use the Declaration of Managua to determine their actions. The project has also been looking at the policies of a number of organizations who are interested in sustainable development. What, Ms. Richler asked, is the development we want to sustain? "Our objective is to work at sustainable community development, including those with disabilities." She referred to a recent statement she had heard that "you can't have peace in the midst of hunger" and said emphatically, "We can't have peace when there are significant groups of people who are completely excluded from the benefits of their communities."

Example: She spoke of disabled veterans in Central America who had been working toward securing services based upon their disability. As a result of learning about the Declaration of Managua and the philosophy behind it, they are now starting to see that categoric programmes are not helping them to exercise their human rights, nor are those programmes really helping them to become part of the community. "We can't have elites among disabilities", Ms. Richler said, "where some get services and some don't."

Ms. Richler also discussed what she called the rising interest in civil society. Some international financial institutions have become interested in civil society; research by Putnam and others claims that a stable civil society leads to economic development. There is growing international recognition that as long as there are excluded groups, there will be social unrest. Social exclusion is one of the roots of social instability. She admitted that watching the activities of some international institutions makes her nervous. She fears that they may be putting the human rights of people with disabilities at risk and pointed out several actions that can imperil such rights. One is handing off responsibility to local communities for education or the provision of social services. While there is the sense that privatization is better and that communities can "do it more cheaply", the end result is that workers lose rights and pay. Yes, it saves, but privatization is not a good measure for protecting rights, because then "the rights of people with disabilities can come at the cost of rights of workers".

Another action that concerned her was promoting philanthropic activities and institutions in countries that have no tradition of philanthropy. The problem with this, she said, was: "Who's deciding what the priorities in social policy should be? Not the people with disabilities, that's for sure. The people deciding are those with the funds." Thus, creating a role for philanthropy is yet another way to give power to the elite. Ms. Richler emphasized that, in determining policy and activities, institutions and planners need to consult with people who have disabilities who can offer insights and suggest solutions that others would never think of. "Participation is not calling them in at the last minute to look over set plans."

The project has had some success in changing attitudes. The InterAmerican Development Bank now has asked them to look at the loan programmes of the bank and of others working in the region:

(a) To see how to include elements in their programmes that would promote the labour and social participation of people with disabilities;

(b) To identify who the actors are that could play a role;

(c) To develop a plan of action for each country and region that would allow the projects to move forward.

In essence, they will be looking at how organizations like the Inter-American Development Bank (IDB) create policies that, in turn, create circumstances that are disabling to participation of people with disabilities. So that, while she is gratified that IDB recognizes their work as important, she says that "the pressure is on to come up with good recommendations that will lead somewhere". She hopes that their model can be applied beyond Central America as well.

Q: Who should we see as responsible for getting information about the project out at the country level?

A: Ms. Richler responded that this question identifies "the nub of the challenge". While the project had funding for three years and pursued its goals with enthusiasm, it is always difficult to get funds for follow-up. This is particularly true when working in areas and with organizations that cannot be reached because they do not have a phone or a fax machine. They had tried to repeat the experience of Managua at the country level and had varying degrees of success. Panama had recreated its own seminar, patterned after Managua, but others had done nothing.

Next, Ms. Reier introduced the second presenter, Dr.Ghassan Rubeiz, (Christian Children's Fund), who is working in Central and Eastern Europe and with the Newly Independent States (NIS). She remarked upon his rich experience working in different regions, including the Middle East. Dr. Rubeiz divided his presentation into two parts. In the first part, he introduced the family model of sponsorship which the Christian Children's Fund uses, and which, he said, is applicable to all forms of children in need. In the second part, he presented three models of individual projects in Eastern Europe, where the family factor is strong.

Dr. Rubeiz described the Christian Children's Fund (CCF) as an international, non-profit, non-sectarian agency working for children in 32 countries, including the United States. The Fund operates through a child sponsorship model, where an adult "who is distant but caring" sponsors a child. The average sponsorship lasts seven years. Benefits are always in the form of community projects focused on a large group of children. Typically, 500 families might be involved. As the project matures, the radius of service widens and reaches more and more families. Projects typically last 10 to 15 years, allowing time to make a real change in the life of the community. CCF's presence, then, is lasting.

Under the sponsorship model:

(a) The whole family is served. A child is sponsored, but others receive help as well;

(b) Parents are in command of the project;

(c) The child's needs are assessed in light of the family's situation;

(d) Parents learn to shift from a passive to an active role. They serve on project committees and boards;

(e) Parents can make or break a project. They hire and fire staff, introduce policy, serve on health committees and other group structures;

(f) There are few staff (3 to 5) and many parent volunteers (50);

(g) Parents serve as advocates for the project within the community. They articulate common concerns about children's issues, and carry on functions that attract the media.

Dr. Rubeiz stated that parents credibility is crucial in changing attitudes and policies.

An infant-mother cerebral palsy project was established in Latvia (where it has since ended) and in Lithuania (where it is ongoing). The project has the following components and activities:

(a) The child and mother stay in a residential setting (what he called a sanatorium) for a four-week programme;

(b) Parents are trained to work with their child during this period;

(c) Staff are trained so that they understand the needs of the parents and of the child;

(d) Training material is developed and given to parents to take home;

(e) Local community training takes place, including orienting the medical personnel in the community to show how to support the needs of the child and family;

(f) The project is put in touch with international resources that can provide further training, information, and assistance;

(g) The parents and child can return to the hospital, when needed;

(h) CCF provides funds and resources for adaptive equipment.

Major results:

(a) Attitudes change toward the child;

(b) The child's behaviour changes;

(c) Staff concerns shift toward accepting parents as a major element in the child's life, seeing them as experts on the child;

(d) Communities now have adaptive equipment that they are replicating from local materials and using.

Although the project in Albania was not actually called the hidden child project, Dr. Rubeiz refers to the project as such, because the name captures the essence of the situation that children with disabilities face in Albania. Most children with disabilities are kept hidden at home. The project (which is being implemented by CCF in partnership with the Independent Albanian Forum of Women, a local non-governmental organization) focused on creating a system of community-based services for the children. Initially, they attempted to train parents together, but this was very difficult because parents were not used to an academic approach. So they have moved to a model where one parent is trained to help another, which is more successful. Staff also have organized community-based social activities, which brings mothers and children together outside the home. These are very successful; mothers and children now have a reason to leave the home. The project also has established a referral system and provided material support, such as seeing that children get the aids they need (e.g., hearing aid, prosthesis).

Institutional child project in Estonia: in Estonia, thousands of children (both with and without disabilities) are put in institutions. The purpose of this demonstration project was to move the children out of the institutions and offer them support through community-based services. The project was implemented in both an urban and a non-urban setting by one local non-governmental organization. The disabilities of the children varied. Social policy in Estonia is a major obstacle to basing services within the community. Although it costs three times more to put a child in an institution than to serve the child within his or her community, directors of the institutions do not want to return children to their homes. As directors, they receive money for the institution caring for the children; they also don't want to lose their jobs by making the institutions unnecessary. In this sense, Dr. Rubeiz stated, the children are victims of social policy. The Government of Estonia has taken over the project, and is very impressed with its results. They have started taking a prevention approach as well, looking at the child before he or she is placed in the institution and trying to prevent institutionalization.

Q: Is CCF doing anything with adolescents? Everything seems to focus upon the young child, and the adolescents seem to fall through cracks.

A: Dr. Rubeiz answered that the projects he had described typically dealt with children up to the age of 16. But CCF, in collaboration with another organization, has looked at issues associated with youth in conflict with the law. They have a kit called Children First!, which is designed to foster capacity-building for non-governmental organizations in a number of areas, including human rights, education, nutrition and health.

Coordinating education and health programmes

Maxine Freund (George Washington University) defined the goal of this concurrent session as understanding the complexities of the services in health, education and welfare. Dr. Freund introduced the first presenter, Veronica Mpagi (Ministry of Education of Uganda), who would discuss Uganda's efforts to collaborate with health professionals and parents in supporting children with disabilities.

Mrs. Mpagi began by describing how, in April 1992, the Government of Uganda agreed with recommendations to democratize education by making it available to all children, including those with disabilities. Meanwhile, the 1987 health policy review commission report had recommended as its main goal health for all by the year 2000. Intersectoral coordination was recommended for all government organizations to ensure achieving this goal. A statutory health advisory council was instituted to advise the Ministry of Health on policies to be followed, especially on necessary health activities and intervention towards those with disabilities. It was not until March 1996, however, that the Ministry of Health had spelled out specific commitment towards disability services. Nevertheless, along with the Ministry of Education, it had created the first integrated action programme through an Inter-ministerial health education expert panel. Along with other relevant ministries, such as that of agriculture, and with the support of UNICEF, they had guided the development of the current basic science and health syllabus for primary schools in Uganda during the 1980s.

In July 1992, with DANIDA support, a national special education programme — Educational and Assessment Resource Services (EARS) — was started. Centres were quickly established in the 39 districts of Uganda by the end of 1996. The main task has been seeing to the consolidation of programme activities in every district. Every effort was made to plan supportive strategies to services development, as well as to coordinate with other disability service givers. Earlier in 1992, the Ministry of Gender and Community Development established the Community Based Rehabilitation (CBR) Programme, which was given the leadership role in coordinating disability services. EARS helped coordinate disability services and called upon the orthopaedic and child-care departments at the national hospital at Mulago to try to meet the demand for more services and to conduct national sensitization seminars and training about disabilities. Both are now slowly decentralizing some of their services to regional centres, where the real action towards disability services takes place. The three ministries hold periodic joint planning meetings and focus attention at the decentralized level of the regional centres.

One outcome of this effort has been the Disability Rehabilitation Section of the Ministry of Health, started in March 1996 with Danish financial support. Commonly referred to as the "disability desk", this unit has an intersectoral subcommittee called the Technical Advisory Committee (TAC). TAC is composed of top local managers of the disability programmes in each of the ministries:

(a) EARS/Special Education in the Ministry of Education;

(b) CBR in the Ministry of Gender and Community Development;

(c) A disability rehabilitation section in the Ministry of Health and a representative from NUDIPU, the National Union of Disabled People in Uganda, an umbrella organization for smaller disability organizations.

TAC handles all inter-ministerial questions and needs that are first identified among the three ministries and are then channelled for appropriate action. TAC is also reinforced by various task forces on individual disabilities, combining relevant personnel of the partner ministries. At the district, county and sub-county levels, where the individual sectoral activities exist, collaborative action is carried out among the three ministries, mainly in the areas of sensitization, identification, assessment and referral. The CBR programme, however, is only in seven districts at the present time, but more are planned for 1997.

Special education programme personnel reach practically all segments of society — politicians, administrators, church organizers, the general public and caretakers for children whose disabilities are so severe that they have to be home-based. They design training exercises for parents to carry out with their own children with disabilities, to minimize development of secondary disabilities, and advise them about self-help development. Special education personnel also counsel parents, caretakers and siblings, as necessary and when feasible. The same personnel work on schools' integration of children with disabilities, sensitizing school communities to:

(a) Change the very negative attitudes towards education of children with disabilities;

(b) Give simple training to classroom teachers;

(c) Monitoring students' progress.

Where the CBR programme is under way, a lot more difference is made. Even at the sub-county level, there are personnel to reach the grass-roots society and individual families more often than the education personnel. Referrals between Ministry of Education and the CBR programme are very common. Despite the limited number of personnel, the structure exists. But unfortunately, since this idea is still fairly new, referrals are not always honoured.

In districts where the three ministries are fully operational, preparations are under way for establishing other districts. EARS began with one district in 1995 and expanded to three more by December 1996. The expansion is promising. EARS personnel work very hard with families to dispel the negative attitudes that exist toward people with disabilities in Uganda, "where the silent practice has been survival of the fittest". Also, an unfortunate development had resulted from earlier donor agencies, who had created boarding schools, keeping children away from their families and giving the children foodstuffs, clothing, sugar, blankets, etc. Most parents then only expected to gain by the child with a disability, and expected someone else to care for them. Now parents are learning to value the child with a disability. They struggle to pay school fees and provide most other needs for these children. This means that parents work hard on making other parents adopt attitudes of acceptance.

Two recent national government moves have boosted disability services:

(a) The 1996 New Constitution provided for representation of people with disabilities on councils up to the Parliament level. Directly elected by the people, these five representatives now include one deaf person, two blind people, and two physically disabled people. Unfortunately, there are no representatives of people with mental disabilities;

(b) The decision to give free education to four primary-school children in every family: first consideration is being given to children with a disability.

In summation, Dr. Freund commented that the Uganda experiences reflect the inter-agency coordination efforts that we hope to cover further in the afternoon break-out groups. She then introduced the second presenter, Ajun B. Bista (Ministry of Education of Nepal). Mr. Bista began by mentioning a few important facts about Nepal:

(a) The Government was a signatory of the Education For All proclamation in 1990;

(b) The Government had implemented primary education programmes by 1992 in 40 out of 70 districts for ages 5 to 16;

(c) Located between India and China, 85 per cent of Nepal is mountainous terrain, with some areas totally inaccessible;

(d) The 1991 census estimated a population of 18 million people; the population now stands at 20 million, a 2.1 per cent growth rate;

(e) 12 per cent of Nepalese are disabled.

Mr. Bista explained that basic primary education focuses on quality and access. Its principle funders are the World Bank, UNICEF, DANIDA, UNDP, the Government of Nepal, and the Governments of Japan and the United Kingdom. The Special Education Programme started in 1964 with the opening of two special education schools: one for blind students, one for deaf. Now, 20 schools have been established for mentally retarded students and four for disabled population. Some 25 of 75 districts have special education programmes funded by the Government of Denmark. Only one school is inclusive. Education for all means:

(a) General awareness: local community acceptance and recognition; need for development of inclusive schools; adaptations in curriculum;

(b) Training of teachers: preparation of teachers includes awareness course; basic training, which is four weeks long, teaches about multi-disability approach; assessments and screening, educational planning, materials development; professional interaction;

(c) Changes to physical environment: includes spacious classrooms; appropriate lighting; good outdoor environment.

Mr. Bista said, "It is our hope that no child is cut off; all are included . . . All children have the right to quality education; all should be included in a classroom closest to home."

He reported that to date 22,000 primary schools have been established in Nepal, even in the remote parts of the country. He cited education models used throughout the country, which include:

(a) Team teaching;
(b) Multi-disability approach;
(c) Support to teachers;
(d) Aides and classroom volunteers;
(e) Itinerant specialists;
(f) Flexibility in curriculum;
(g) Mobile teaching team;
(h) Child-to-child approach.

Since the country is very mountainous and there are no basic road facilities, it is very difficult to use wheelchairs, so parents often need to carry such children. The Government of Nepal has promised to provide access, but it is slow in being realized. Even though we have residential facilities and segregated schools, we are moving towards integrated settings. There are, however, distinct barriers to full integration of children with disabilities: (a) terrain; (b) lack of teacher training; (c) social attitudes and behaviours: the assumption is that disabled children do not contribute; and (d) lack of early intervention. Some attitudes are changing. Parents used to hide their disabled children at home; now they bring such children to the local school for diagnosis and programme support. Coordinated with health ministries, the Ministry of Education is attempting to present an integrated approach. Together they are trying to make local and international linkages with universities and organizations in neighbouring countries.

Q: Aurora L. Estrella (Partners in Policy of the Philippines asked, "Do you have statistics on the number of children with disabilities served before the programme started and the number of children now being served?"

A: Mr. Bista responded, "We did a survey (it's ongoing) in 20 out of 75 schools. This survey pinpointed the type and the degree of disability, so it helps in allocating resources to correct schools."

Mr. Bista continued by emphasizing the need to establish an infrastructure for children with disabilities in his country. He pointed out that 14 per cent of government funding goes to education, despite its promise to move it up to 16 per cent. Fifty-five per cent of this budget then goes to basic and private education. With 22,000 schools, resources are stretched. He concluded by saying that the Ministry of Education plans to work with the Health Ministry this year to test an integrated approach for services and programmes. Dr. Freund underscored that Nepal's emerging model is challenged by the difficult terrain issue.

Finally, Dr. Freund introduced Sue Stubb (Save the Children of the United Kingdom/Save the Children Fund's Alliance, a partnership with Norway/ International Consortium on Disabilities). Ms. Stubbs began with a brief history of Save the Children and then presented an Integrated Services Model that grew out of Save the Children's experiences in the mid-1980s in East Africa. There, WHO began with a community-based rehabilitation (CBR) model that delivered therapy training services in homes where they expected people to perform such therapies. "They soon realized", Ms. Stubbs commented, "that this institution-based (home) service delivery model was isolating, only benefited the individual child in the household, and had no impact on the community or schools." Now, CBR models in the southern Africa region have taken a broader community approach — they have gone into the community, listened to mothers and heard two needs to be addressed: poverty and isolation, not rehabilitation.

As a result of these experiences, Save the Children decided to address poverty by (a) empowering families in developing self-help groups, and (b) giving grants and loans to promote self-esteem. Save the Children addressed the issue of isolation at all levels, such as attitudes changes and building up self-help groups so that rehabilitation could be carried through. The programmes targeted community barriers and spent years on community awareness and education by promoting self-help groups. One problem of CBR programmes was that it undermined natural community support. Prior to CBR coming into a home, a neighbour was coming over to help the mother with the disabled child. Once CBR personnel came to help, the neighbour stopped coming. The notion of such community support is lost on Western countries, where Western parents of children with disabilities hold their own child back in classes and "the child with a disability is viewed as taking too much of the teacher's time". Ms. Stubbs described Desuto parents as believing that the child with a disability ". . . teaches all children social responsibility and community responsibility . . . We are trying to shift this [issue] to natural supports."

In the new model, organizations and disabled advocates work together to teach parents to see their child with a disability as a valuable contributing member of the community. Through inclusive education, CBR attempts to make partnerships with disabled activists work for parent advocacy legislation and policy changes, as well as to fulfill the goal of "unlocking community potential". One of the tools to accomplish this is to have people with disabilities work with other people with disabilities. Example: An adult person with Down's syndrome assisted a blind person in daily living skills. By building the capacity of children, the key role of using a self-help approach is to focus attention on unlocking potential, to target the barriers to inclusion, and to create "solidarity around disabled children". Example: A child with a disability uses a wheelchair, but there are no roads. Since he kept falling out of his chair, the community rebuilt the road to school, reflecting solidarity around the child's welfare.

In general, special education was a system based on the belief that there should be an absolute division from basic education programming. Integrated education was based on the rehabilitative model and seemed to require that you "fit the child to the school", or mould the child to fit the programme. Inclusive education, however, is based on the belief that the child is disabled by the barriers within the community. The premise now is to accept reality — that all children are different and that each should be valued for the contribution he or she makes to the community. Example: In China, policy makers thought it would be more expensive to build segregated schools for the disabled, so they included children starting in kindergarten and realized that this was the best way. Since special needs start in kindergarten, all curriculum is "child focused", utilizing team teaching and cluster schools.

Integrated education became the catalyst for changing the system and removing the barriers. Differences are a reality. "We must learn from economically poorer countries that education takes place in a wide range of settings, and that each country/community should be able to support even the severely disabled, even in the home if the mother needs support there. That is inclusion: inclusion in the overall community." Ms. Stubbs asserted that inclusive schools are flexible, child-centred in that they teach all pupils, and encourage teachers with disabilities to become involved. "The lesson is that education is something that happens in all levels of the community . . . education is broader than the school setting. It can happen in the home and the community as well." Example: In Mozambique, deaf adults are working in neighbourhoods with deaf children. Ms. Stubbs concluded her remarks by making the following summary statement: "Inclusive development is the aim: valuing differences; providing access for all children; combating discrimination; promoting a children's agenda and adult literacy; and integrating health and education services."

Public awareness and information sharing

Christine Fowles (African Development Foundation) emphasized the importance of positive community and societal attitudes regarding childhood disability in making children with disabilities welcomed members of their schools and communities. She introduced the first presenter, Suzanne Ripley (Academy for Educational Development), who has a bachelor's degree in English and education, a master's degree in mass communication, and is working on a doctorate in social service. Ms. Ripley has worked at the Academy's National Information Centre for Children and Youth with Disabilities since 1984, a few years after the Centre began; her statement is set out below.

"Today I'm going to tell you about the Centre, but as I tell you about where we are now, don't forget that this is only after 20 years. I hope it won't take any of you 20 years to get to where we are today. By working together we can work faster, share information, and avoid the things that we at the Centre found out — through experience — don't work.

"I started in the information business about 20 years ago with a bunch of mothers sitting around in a kitchen with a box of index cards. We knew we needed more information to answer questions we had, so we got together and collected information. We wrote down the information on organizations we found out about on our index cards and kept them in boxes. I have a personal interest in disabilities. Both my sons were born with a rare genetic disorder that gives them a number of disabilities, including mental retardation, and my older son has cerebral palsy and is legally blind. (Ms. Ripley circulated pictures of her sons Alex, 21, and Joe, 19.)

"In 1975, the Government of the United States passed a law in which children with disabilities were guaranteed a free and appropriate education. In 1990, this law was revised as the Individuals with Disabilities Education Act. These laws, dealing with the education of children with disabilities, mandated that an information centre was to be set up to respond to questions from the public about the education of children with disabilities. That's how the Centre was started.

"The mandate of the Centre is simple: to respond to requests from the public about children with disabilities. Anyone can contact the Centre for information: teachers, parents, bus drivers, architects, policy makers, journalists, administrators, etc. Information is what people need to reduce or resolve a problem. They need information so that they can make decisions. And the information must be accurate, current and, most importantly, relevant. In order for an information centre to provide relevant information, the staff have to understand the nature of the audience's problems. They need to talk to their audience.

"The Centre guides parents, researchers, educators, policy makers, students, children, medical people and others to information sources. People don't contact information centres with questions — they contact us with problems. They call us and describe a situation. But they don't necessarily know what to ask, and whom to ask.

Example #1: A mother calls the Centre and says, "I've just found out that my newborn daughter has Down's syndrome. I don't know exactly what that means. The doctor says she may need heart surgery and may have to be in the hospital for quite some time. I don't have the money for that. And I have two other young children at home that I need to care for."

"What was this mother's question? Our information specialists listen to situations like this and identify what people need. In this case, we would send the mother a fact sheet on Down's syndrome, a state sheet for her state — this lists all state-level resources, as well as parent groups. We'd send her a parent guide on accessing programmes for infants, toddlers and preschoolers. We'd also link her to organizations that could provide respite care.

"We take people's problems and provide them with information, the questions they need to ask, and which people they need to ask which question. Over the years, certain situations have become familiar. Therefore, we've developed publications to address those familiar problems.

"Example #2: A teacher calls and says one of her students isn't coming along very well. He seems to be having problems learning and isn't keeping up in class. We would send this teacher publications on assessing children for the presence of a disability, and bibliographies on assessing children for disabilities for the school, and perhaps the version for parents, so that she could give it to the parents of the child.

"In order to be most effective we need staff who know the issues. Our staff is made up of: (a) parents of kids with disabilities; (b) professionals: those schooled in special education/ disabilities, and some former educators; and (c) people with disabilities. We also have a resource network or organizations that we link people to — national-, state- and local-level organizations.

"An information centre can only be useful if people know it's there. Therefore, we do lots of outreach. How? By:

(a) Mailings to those on our mailing list;

(b) Placing ads/announcements in journals and newsletters;

(c) Distributing brochures and publications catalogues at conferences;

(d) Sending our publications to organizations;

(e) Public service announcements on television;

(f) Providing information over the Internet with our Web and gopher sites (the Centre can also be reached through e-mail).

"In order to keep tabs on how effective we are, we do evaluations. We keep records about who contacts us. So we know what issues people are most interested in, and we also see who we are reaching.

"Parents and professionals need information, but they also really need to know that they are not alone. They need to know that other people have experienced and are going through the same things they are. They need to connect to a community that can give them support. In order for people to make a decision they need to know all their options. We don't have all the answers. But we do understand the questions, and if we don't have the answer we know who to refer people to. We give people hope, but most of all we hope to give them direction.

"Some statistics on the Centre from 1996:

(a) Some 42,000 people were served this past year: 50 per cent parents, 50 per cent professionals, a total of 48,000 inquiries;

(b) We have heard from every state and territory in the United States, and now, with our site on the Internet, we are beginning to hear from international locations;

(c) We have over 50 publications to answer your questions;

(d) We have over 1,000 organizations in our database.

"But please remember, this is after 20 years. When we started, we didn't have anything. We didn't have any databases, we didn't have a Web site. We didn't even have any computers. The only things we had were phones and lots of paper: phones that we could only call out on; no one could call us. We talked to everyone we could at every conference and meeting. We collected all the free material we could from other organizations. Then we built on that. We answered requests through the mail only. Our supplies were donated. People gave us the desks, chairs and eventually computers that they didn't want or need anymore. Half of the first staff we had were paid, half volunteer. Now we can help other fledgling organizations start up. We can give them materials to start with. You don't need much money to start. Once you show people how valuable a service you are providing and how much you are doing, you will gain support."

Ms. Fowles then introduced the second presentation, which focused on grass-roots public awareness campaigns to spread positive information about children and adults with disabilities in Mali and Uganda. Mr. Souleymane Diallo (Mali Association for Prevention of Mental Deficiencies in Children (AMALDEME) has served as the Director of Education at AMALDEME and in 1996 was the director of Mali's Special Olympics. He collaborates on various levels with other non-governmental organizations and is the Chairman of the board of organizations that work in Action on Disability and Development (ADD); his statement to the Workshop is set out below.

"I would first like to thank the African Development Foundation for sponsoring my participation in this Workshop. I also give thanks to all the organizations who organized this Workshop, especially AED, DANIEF and FISE. My talk will be about changing attitudes toward disabled people in developing countries.

"AMALDEME was founded by the mother of two daughters who are mentally disabled. She founded AMALDEME in 1984, but activities weren't really started until 1987. In order to reach AMALDEME's goals, she created a centre that is the core of all activities. AMALDEME has several goals:

(a) To study mental deficiencies and diseases associated with it;

(b) To work with expectant mothers to better prenatal care;

(c) To work with children with disabilities to help them find jobs — to train them.

"There are several divisions of AMALDEME:

(a) A therapy division;

(b) An education division that deals with both the education of children with disabilities who can be mainstreamed and those with severe disabilities who cannot be mainstreamed;

(c) A division for extracurricular activities, including sports;

(d) A division for vocational education (training of skills, helping people do better at what they are already doing);

(e) A community-based division.

"How are disabilities viewed in Mali? In Africa, people say that nothing happens by chance. If a child is born with a disability, it may be viewed as a punishment for the family. It depends upon the circumstances during which the child is born. If the child is born at a time when positive things are happening, then the child is viewed as a good omen. If the child is born at a time when negative things are happening, then the child is viewed as a bad omen — as a punishment for the family. If neither good or bad things are happening, then the child is considered to be afflicted with a disease. If this third scenario happens, then the parents want the child cured instantly. They take the child from witch doctor to witch doctor trying to cure the child. In such cases, the child often becomes worse due to these attempted healings; and by the time they reach the AMALDEME centre, they are more disabled than when they were born.

"AMALDEME is trying to educate the people and change attitudes. We are trying to get more children with disabilities mainstreamed so they are not left on the sidelines. How do we change attitudes? Several ways:

(a) We have started an early intervention centre. We are developing different types of intervention, such as play therapy. The idea is to make parents interact with other parents so that they learn from each other and learn what children can and cannot do. We use play to help evaluate children. Then we follow up these evaluations by visiting them at home;

(b) Outreach. AMALDEME has made a videotape about a family with an autistic child. The video dealt with prejudice against mental disabilities. It follows the family's life up until the time they go to the AMALDEME clinic. Efforts like this make the community more aware of problems;

(c) One of AMALDEME's goals is to make people aware of disabled children's potential. In order to do so, AMALDEME has started activities that make money. These money-making activities enable kids to get in touch with and be involved in the community, breaking down preconceptions of disabled kids. Money-making activities include: (i) a woodworking centre where kids produce wooden products, including toys; (ii) a renting service which rents chairs and tables for parties; (iii) a milling project; (iv) a water-selling service; and (v) an agreement from the Government of Mali to buy goods from the centre.

"The barriers that exist for children with disabilities are slowly coming down. The Government is being supportive, and has even made October "Mental Disabilities Month." The Government is helping to demystify children with disabilities. AMALDEME is also trying to strengthen the community. It is organizing mothers of kids with disabilities so that they support each other and gather resources to help their children. They are educating these mothers about their children's special needs. AMALDEME has a team of people with many skills: rehabilitation therapists, physical therapists, speech therapists and others."

Finally, Ms. Fowles introduced the third presenter, Ms. Maria Kangere (Community-Based Rehabilitation Alliance (COMBRA) of Uganda) to describe grass-roots awareness activities under way in Uganda. Ms. Kangere is a trained physiotherapist and community-based rehabilitation trainer. She is a co-founder of COMBRA, which started in 1990 as an organization that trains grass-roots trainers. Maria has a special place in her heart for children with disabilities, especially those with cerebral palsy; her statement is set out below..

"Good morning. I bring you greetings from Uganda! I have always had an interest in children with handicaps. My older brother had a mental illness. At that time, you were never allowed to talk about it, not even in a whisper. It was a very stigmatizing condition for the whole family. The only time we were free of it was after my brother died, because in my culture no one speaks of the dead.

"COMBRA's mission is to improve the lives of people with disabilities. Our emphasis is to change negative attitudes in society. COMBRA runs 16-week courses to train people who will work with families having kids with disabilities. The main components of what we do are:

(a) Training;

(b) Appropriate technology. Since resources are scarce we teach our trainers how to be creative and create assistive devices with materials at hand;

(c) Information dissemination. We have a small information centre with a library that people can use, and we are producing newsletters and leaflets;

(d) Income generation. We run a small clinic in town to help finance our efforts.

"We work with very poor communities. It is very hard to penetrate communities and to gain trust. People live in shanties. There is garbage all over. The area is very swampy and the living conditions very poor. Because the water table is very high and the ground swampy, it is a perfect breeding ground for mosquitos. Malaria is rampant. Many children are born healthy but get malaria by the age of five, and from the malaria fever become mentally retarded.

"We try to talk to people and identify and solve problems. COMBRA tries to work with families to create support groups. We also try to get the children with disabilities integrated into the schools. This is very hard because the classes are very large — 150 kids in each class. The normal children have a hard time keeping up and getting the attention they need, so the kids with disabilities have an even harder time.

"The attitude in Uganda toward people with disabilities differs in every community but is generally negative. Children with disabilities are viewed as a punishment, many times toward the mother. It is assumed that the mother may have broken a taboo during her pregnancy, such as eating eggs. Communities have such strong beliefs in their myths that it is very challenging to change their attitudes. Families break down when a child has a disability. Many times, the mothers are left to raise the child themselves.

"In order to change these negative attitudes, COMBRA has used different techniques to educate the public about people with disabilities:

(a) We have people with disabilities who have achieved success come and speak to the people so they can see how much people with disabilities are capable of;

(b) We foster community awareness through local councils. We teach the community leaders — chiefs, teachers and church leaders — sensitivity, and teach them the scientific causes of disabilities. Then these leaders can influence people within their communities;

(c) We also educate the parents by taking them on field trips to visit other families with disabilities. They see the programmes that others have in place, and are then inspired to replicate these programmes back in their own communities. Mothers are getting together to support each other and bring about solutions.

"Helping people with disabilities is on the bottom of the priority list for many of these very poor communities. They are most concerned about getting enough food and water to live on. To help mothers, COMBRA has started a programme that gives them an industry they can do at home so that they can stay with their disabled child but still make an income.

"We have had success at changing the attitudinal barriers in Uganda. People with disabilities used to feel lonely, inferior and guilty for having a disability. But now, communities are more educated about the causes and preventions of disabilities, and neighbours are starting to help families with children with disabilities. Now that they know some of the causes of disabilities, communities are starting to work to prevent them. The people are more educated about disabilities, and in a way this is a problem because now they are demanding services and there are not enough resources to meet these demands. It is especially hard to meet the needs of children with severe disabilities.

"At the national level, Uganda has gone through many civil wars. After surviving all those hardships, people are starting to demand a better way of life. The disabled people of Uganda are putting pressure on the Government. They made sure that disabled people's rights were written into the constitution of Uganda. The Uganda Constitution is available in braille so that blind people can know and fight for their rights. (The Uganda Constitution was written in 1995 and a person with disabilities was involved.) Now there are representatives on disability issues from different parts of the country.

"COMBRA has also worked with the media to stop using negative language in regards to people with disabilities. COMBRA has recently held a sensitivity seminar for journalists so that they are more aware of the proper language to use. At present, the disability organizations of Uganda are focused on adults, not kids. However, the Government is starting programmes for disabled kids. We have not totally succeeded, but we are getting there."

Questions for Ms. Kangere:

Q. How do you approach the different tribes with your disability awareness campaign?

A. There are many different languages spoken by all the different tribes. However, there are four major languages in Uganda. We use those languages. We use radio and other methods to reach them. We don't interfere in their cultural rituals. We have community leaders talk to them.

Q. Do you have a way to feed information to the government policy makers? Do you have a dialogue with them?

A. We work at the grass-roots level. There is a national council on disabilities that reaches the national level.

Q. How do you remove negative attitudes?

A. Slowly. We can't remove them entirely. But it is gradually getting better. Now we have a deaf person in our Parliament. We train parents that having a child with a disability is okay. We take them to visit another family with a disabled child. It goes very slowly. Not everyone changes.

Questions for Ms. Ripley:

Q. As you get involved internationally more and more, how does that work out with your funding? How are you expanding capabilities?

A. The Centre is only funded to work in the United States. Our Internet site reaches people internationally. We are talking to groups who are planning to work internationally. That's one of the reasons we're here today. We can help international groups, and through them help people internationally.

Protection and rights of children with disabilities

Ms. Zuweina Khamis (Association of the Disabled of Zanzibar/Eastern Africa Federation of the Disabled) introduced the session. She spoke briefly, noting that "children's rights are human rights. Maybe that's easy to say, but children's rights in the developing world are not always well planned". Ms. Khamis then introduced the two presentations.

Charlotte V. McClain (University of the Western Cape (South Africa)) began by defining some of the activities of the University's Community Law Centre. She stated that there is a gender unit, a democracy unit and a unit on children's rights, of which she is a part. Her unit focuses on children's rights generally, and her specific area of interest is children in especially difficult circumstances. Children classified in this group include street children, child prostitutes and children who have entered the juvenile justice system.

Ms. McClain stated that the most striking component in her work was that disability was so prevalent in each of these vulnerable groups, and no one was working with them. She observed that the correlation has not been made between the conditions in which these children live and the rate and occurrence of disability among them.

In addition to her work at the Centre, Ms. McClain was recently tapped by the office of the Deputy President of South Africa to work on policy recommendations for handling comprehensive legislation regarding disability issues, also known as the "White Paper". In her work on this policy piece, Ms. McClain concluded that South African society has "contextualized disability in the area of social exclusion". This has been demonstrated in the inequality experienced by vulnerable groups in South Africa: children ("girls are doubly disadvantaged"), women, the elderly, the disabled and people living in rural areas. The issues surrounding these groups are intertwined: for example, children's rights are closely linked with women's rights, since women are often the caretakers of children and people with disabilities.

Children with disabilities have been excluded from education and its benefits, and are likely to become dependent on the Government. People with disabilities were extremely marginalized during apartheid, "really doubly discriminated". The new South African Constitution places a high emphasis on personal dignity, prohibiting discrimination on the basis of race, colour, gender or disability. However, current legislation takes a piecemeal approach to addressing disability.

The White Paper, expected to be adopted by Parliament early in 1997, insists that disability issues are human rights and development issues, and should be considered accordingly. In addition, the policy recommends that disability issues, such as education and transportation, should be handled by the appropriate ministry rather than relegated to the Welfare Ministry. Ms. McClain insisted that disability must be a consideration in all of the activities of the Government: "the twining of welfare rights and human rights". This would enable the Government to plan in a coherent and comprehensive manner for all its citizens. The aim is to craft and implement a comprehensive piece of legislation similar to the Americans for Disabilities Act.

However, as Ms. McClain pointed out, legislation is one thing, actual implementation is another. Making information available to the people that need it is critical. People with disabilities may have rights on paper, but "it makes no sense to have rights if people don't know they have them". The Centre is working to translate several large pieces of legislation (including policy on schools, criminal procedures and the health care act) into common language (parlance) and into the 11 languages recognized by the constitution. This information would be available in a variety of formats as well.

Ms. McClain stated that another challenge to implementation is geography. South Africa has a very rural population. In March 1997, offices will be opening up in each of the provinces to accommodate information needs and services since provincial offices are accessed more readily than national. Ms. McClain noted that they are just trying to reach people: "Our struggle is still a very basic struggle: the struggle to provide services. South Africa still has a dual system — before it was white and black, now it is urban and rural. These are the things we have to keep in mind when developing legislation." She concluded by stating that she would like to hear what other countries are doing to reach their rural populations.

Q. How can you apply international instruments and legislation?

A. Ms. McClain replied that Section 19 of the South African Constitution allows for the application of international law principles where domestic law is lacking. Therefore, international laws, including the Convention on the Rights of the Child and the Standard Rules, may be invoked when necessary, though she noted that there are not many lawyers or judges trained in the field of international law.

Dr. Garé Fabila de Zaldo (Mexican Confederation on Behalf of People with Mental Disabilities/Panel of Experts on Disability for the Standard Rules) stated that it is very important to hear what is happening in developing countries: "We need to see what is happening and get together as an international force to push our Governments to act. It is easy for them to forget. But for us, it is different."

Ms. Penny Platt (University of Manchester) noted that an effective way of reaching rural populations is to work through local councils, finding out when they are meeting and doing whatever it takes to reach the meeting. Once the information is presented there, the chief or council of elders will take care of informing their communities.

Ms. Lilliam Pollo (United States Council on Disability) stated that information is not always enough to implement law. The first step is crafting legislation, the second step is informing the population. Ultimately, the third step must be exercising these laws in court. Citing ADA and IDEA as examples, Ms. Pollo remarked: "Without the case law, [the laws] don't mean anything."

Mr. Eric Rosenthal, (Mental Disability Rights International) explained that Mental Disability Rights International (MDRI) is an international human rights organization committed to building disability rights awareness for people with mental illness or mental retardation. He said that MDRI is funded jointly by the Bazelon Center for Mental Health Law, the leading civil rights law firm for mental disability in the United States, and the American University Center for Human Rights, an international human rights centre.

Domestically, MDRI works to influence the international development community in Washington, D.C., building disability rights awareness that can be incorporated into global development work. However, MDRI's primary focus is working internationally to bolster support for locally based advocacy groups abroad.

Although countries and cultures are different, Mr. Rosenthal noted that the issues surrounding mental disability are strikingly similar wherever you go. International law has made some great strides, but the challenge is in transforming the recognition of people with disabilities in legislation to the enforcement of these laws. He cited the example of Hungary, the world's 40th richest country, where long-term institutionalization and segregation from society is still the standard.

Mr. Rosenthal distributed some notes adapted from the Yale Declaration on the Protection and Rights of Children with Disabilities: Recommendations for International Co-operation and Support. This working committee document lists five recommendations for achieving its objective:

(a) Recognize disability rights as human rights. Several international laws are in place supporting disability rights as human rights, including the Convention on the Rights of the Child, the International Covenant on Civil and Political Rights, and the European Convention on Human Rights. Mr. Rosenthal noted that these laws can be applied when domestic laws are lacking, as was done recently in New York State. He remarked that the "genius" in the Convention on the Rights of the Child is the positive emphasis on supportive services and insistence on the integration of children with disabilities into the community. He emphasized the latter, noting that "the principle of community integration has been adopted into international law, and we should use these mechanisms whenever possible";

(b) Include disability rights within all programmes, including civil society and democratization programmes. Disability rights need to be built into all programmes to be truly effective. This is not just a policy matter — it is an international obligation. Small grass-roots organizations spread their meagre resources very far without domestic or international recognition. Including disability rights in all programmes would shift focus and support to these organizations;

(c) Promote locally based advocacy. Mr. Rosenthal observed that locally based advocacy groups have "an incredible level of sophistication". They know how to push their issues (and how to spread their resources), but they need help in developing linkages with other groups, especially in their own country, as well as abroad. Again, problems are very similar in developing countries, and each country does not have to reinvent the wheel. Networking and exchange help to empower and inspire;

(d) Promote systemic adoption of best practices. Model programmes should never be a temporary solution. In many cases, Governments will not support locally based solutions even though they are pouring money into long-term institutions. By connecting locally based groups, model programme information can be shared. If you can present the big picture, highlighting these model programmes at the local level as an alternative, the Government can be persuaded to shift resources from the institutions to the programmes, and these programmes can help people with disabilities away from the institutional setting;

(e) Promote inclusive national and international planning for human rights enforcement and reform of service and support systems. The Standard Rules recognize that people with disabilities should participate at every level of policy planning and implementation. International donor agencies need to address how they can incorporate the locally based groups now working in isolation. By bolstering the locally based groups, agencies can affect people with disabilities in a positive way, while ensuring the success of their programmes.

Next, Catherine O'Malley of MDRI explained that the Americas Group for the Rights of People with Disabilities is a joint project of MDRI and the Pan American Health Organization. The Americas Group promotes the rights of children and adults with disabilities by drawing on the experience of participants of diverse backgrounds, with a special emphasis on locally based advocacy groups. Ms. O'Malley emphasized that the "Americas Group" was plural, not possessive: it is an effort aimed equally at North, Central and South America. Emphasizing integration and creating customer-driven services, the Americas Group will further its goal in four ways:

(a) Fostering exchange among consumers, self-advocates, family, mental health professionals, Governments, education agencies, human rights agencies and regional and international donors to share ideas, experience and best practices;

(b) Building regional advocacy training workshops taught by peers. These workshops will discuss the Standard Rules, how to apply them, how to build alliances for systemic reform, and finding the guidelines to strengthen legislation and to press for implementation;

(c) Fostering a communication and collaboration network. Networks for mental disability groups are less developed than in the physical disability arena. The aim is to link consumer and grass-roots advocacy organizations with each other and with their Governments, with the expectation that "affinity groups" will form around common issues of interest, such as women and disabilities, children and disabilities;

(d) Forming a regional constituency. As the participants in the Americas Group draw together, a strong regional link is formed that can push for results in the creation, recognition and enforcement of rights for children with disabilities. Working on the basis of the Organization of American States' Inter-American Covenant of Rights to prohibit discrimination against people with disabilities, the Americas Group wants to adopt a meaningful convention that groups know about and that they can encourage their Governments to support, creating a framework for influencing government that includes people with disabilities.

Some 150 organizations in 21 countries of the Americas have already expressed their interest in joining the Americas Group. Drawing upon varied strengths, "the Americas Group creates space for voices that are not often heard — the voice of children and people with disabilities."

Finally, Charlotte Oldham-Moore of MDRI discussed mental disability issues in Romania. In 1989, Romania began the transition to democracy. At that time, 80,000 children were in orphanages. Despite the worldwide attention that the Romanian orphanages attracted, the number of children institutionalized grew to 105,000 in 1992.

Although international donor agencies made some improvements in services, the agencies made no real effort to promote the integration of children with disabilities into the community. Romania has a complex system of custodial caretaker institutions, but family supports in the community are absent. When a family is considered unable to meet a child's needs, institutionalization is the only presented solution for "irrecuperables". Families are broken up, with little placement of children with disabilities in natural or adoptive families.

Ms. Oldham-Moore stated that international agencies and non-governmental organizations must promote community integration for children with disabilities to prevent further human rights abuses. They must also engage and support local advocacy organizations critical to the success of reform programmes. At present, the MDRI Central/Eastern European Initiative is working with a large family organization to increase advocacy. This 2000-member organization is: building upon the work of non-governmental organizations to train experts in service provision, working to challenge the Government, and establishing linkages to support and teach about model programmes. Ms. Oldham-Moore stated that there is a real momentum building in these locally based groups: "People are hungry for advocacy, and they are hungry for change. They need our support."

Pre-workshop activities

Some 33 Global Workshop participants from 21 developing countries took part in pre-workshop activities especially designed for them. Each activity was intended to provide technical assistance and training, as well as opportunities for the participants to network and share their own experiences with children with disabilities and their families. Beginning with an orientation, conducted by the Academy for Educational Development, participants were given logistical information about the upcoming activities, as well as a substantive review of the workshop agenda.

Next, the participants took part in a discussion on the theme "The role of empowerment, networking and advocacy in grass-roots and non-governmental organizations' capacity-building", conducted by the African Development Foundation and the World Institute on Disability. The discussion provided a lively exchange of their knowledge of the barriers to full inclusion of children with disabilities and the strategies being used to overcome those barriers, including the identification of groups to work within each country to achieve change.

The participants were taken by minibuses to several school sites in Anne Arundel County, Maryland, to visit inclusive classroom settings and early intervention programmes. At each location, the participants were given background information on each programme by teachers, health and social service practitioners. Then they observed several inclusive classroom settings, interacted with teachers and students, a parent of a preschool child, and Maryland state education officials. These site visit arrangements were made by the United States Department of Education, Office of Special Education and Rehabilitative Services and The George Washington University.

Finally, the United States Department of Health and Human Services, Maternal and Child Health Bureau, presented a talk on the theme "The communities can experience: establishing family-centred, community-based services", as a panel discussion of the principles guiding this programme, as well as its application in developing countries and in Central and Eastern Europe. The panel then worked with the participants to develop action strategies applicable to their own countries.

Thirty-fifth session of the Commission for Social Development

Mr. Bengt Lindqvist, Special Rapporteur on Disability of the Commission for Social Development, made an oral presentation on the findings of the report on his three-year appointment and their implications for future work. He noted the high level of responses by Governments (85 replies) and non-governmental organizations (165 replies). One result of the adoption of the Standard Rules on Equalization of Opportunities for Persons with Disabilities by the General Assembly in 1993 has been the growing awareness among Governments of disability issues in all regions, an observed rethinking of policies, and the introduction of national legislation based upon the Rules. An important finding has been the growing pattern of cooperation among Governments, organizations of persons with disabilities and the non-governmental community. Concerned members of the United Nations system have made important contributions as well. The Special Rapporteur observed that positive trends need to be encouraged and strengthened, but there is still much to be done, particularly in terms of mainstreaming. The monitoring exercise should continue since it provides a basis for reviewing and discussing experiences. There is a need for new initiatives as well, such as strengthened advisory services to Governments.

All delegations participating in the discussion supported the renewal of the mandate of the Special Rapporteur and his Panel of Experts for an additional three years to the year 2000.

Many delegations reported on initiatives that their Governments had taken to further implementation of the Standard Rules. For instance, the European Union had adopted a resolution on equality of opportunities for people with disabilities, had initiated information and awareness campaigns and had produced a manual on accessibility. South Africa had established an office on the status of disabled persons in the Office of the Deputy President of the Republic, and disability issues were being incorporated in public policies. One representative of a non-governmental organization commented that the Standard Rules represent an important normative statement on equalizing of opportunities of persons with disabilities.

Several delegations stated their full agreement with the areas identified by the Special Rapporteur for further action: children with disabilities, gender perspective, and housing and shelter. Several delegations directed special attention to the question of children with disabilities, and the special situation of children disabled in armed conflicts, since they represent an especially vulnerable group of the population; a representative of a non-governmental organization noted that children with disabilities will become adults with disabilities in the absence of appropriate action. Other issues cited by delegations include further development of the human rights perspective, the need to address employment opportunities, empowerment and sustainable livelihoods of persons with disabilities, and the need to incorporate the Standard Rules in poverty eradication initiatives.

Many delegations commented on the need for the continuation of the monitoring exercise and for dissemination of information on experiences in promoting and implementing the Standard Rules. Delegations called for strengthened cooperation between the United Nations and the non-governmental community to promote the Standard Rules at the country level; one commented on the importance of the United Nations Secretariat facilitating partnerships in support of the Standard Rules. Another delegation commented upon contributions which could be made by such regional-level initiatives as the Asia and Pacific Decade of Disabled Persons (1993-2002). A representative of a non-governmental organization stated that regional offices of her organization were prepared to promote, train and contribute to monitoring the implementation of the Standard Rules.

Several delegations addressed the following questions to the Special Rapporteur:

(a) In countries without disability policies in place, would the Special Rapporteur use a best practices or a case-by-case approach to policy development ?

(b) If his mandate were renewed, what would be the priorities for Mr. Lindqvist?

(c) How could Governments cooperate best to promote and implement the Standard Rules within the framework of their own regional initiatives on disability?

(d) If his mandate were renewed, how would the Special Rapporteur propose to address the human rights perspective in the context of the Standard Rules?

(e) If his mandate were renewed, how would the Special Rapporteur propose to address the question of children with disabilities, and what would he propose to improve the situation of children with disabilities?

In reply, the Special Rapporteur made the following comments:

(a) He stated that three priorities for further action were identified in his report: children with disabilities, gender, and housing and shelter. He would also direct special attention to the matter of mainstreaming the disability perspective in national development, which he felt would contribute to a normalizing of responsibilities in the field of disability;

(b) As to linking the monitoring exercise with the emerging human rights agenda, he stated that he was of the view that the existing human rights entities of the United Nations system can best do this; an appropriate role for the United Nations is to serve as catalyst in the identification of issues and trends;

(c) He further noted the need to develop national capacities to promote, implement and monitor implementation of the Standard Rules. There is need for more work in the field of statistics and disability, including identification of indicators;

(d) With regard to policy development, he expressed the view that he knew of no current compilation of good practice, although many examples exist. In his view, the United Nations could usefully document this;

(e) He stated that since work on the Convention on the Rights of the Child had preceded the Standard Rules and since conventions were of greater policy importance than rules, he was of the view that there was no need for the Standard Rules to have mirrored the Convention;

(f) He stated that the Asia and Pacific Decade of Disabled Persons complemented the Standard Rules, and that much could be gained through closer linking of efforts.

NGO statement

The statement set out below was submitted to the Secretary-General of the United Nations on 20 February 1997 by Inclusion International, Rehabilitation International, World Federation of the Deaf, World Blind Union and Disabled Peoples' International.

The disability organizations meeting you today are the most powerful in the world. You'll find us in all countries working for full participation of persons with disability and society — fighting for human rights and against abuse and discrimination.

In spite of all the efforts made by the United Nations and the non-governmental organizations, the vast majority of the world's disabled people are living under miserable conditions according to the 1993 United Nations report on human rights of disabled persons.

Persons with disability must be made more visible in all relevant activities of programmes of the United Nations and in the policies of its Member States.

The World Summit for Social Development, held at Copenhagen in 1995, gave promises in that direction. In follow up, however, the Economic Social Council now just talks about "disadvantages and other factors among disadvantaged groups". The current United Nations emphasis on poverty eradication is another chance to highlight the fact that people with disability are the poorest among the poor.

To make disability more visible, we need the support of the Secretary-General. We also need a secretariat with a capacity to act as the focal point of coordination. We ask that further thought be given to how we international disability organizations can help you with this task.

You, Mr. Secretary-General, have often mentioned the importance of close links between the United Nations and civil society. We, the non-governmental organizations, represent the interest of women and men with disabilities worldwide. We are certain you will, and really are able to, assist us to increase our efforts to work toward full participation, in close cooperation with the United Nations and its specialized agencies. Together, we should advise and support Member States in working towards the goal of equalization of opportunities for persons with disabilities.

The United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities are a most progressive human rights instrument, and have been widely accepted by many Governments and certainly all disability non-governmental organizations. The Standard Rules represent a move away from viewing disability as a welfare concept to a rights-based approach, integrating disability into all areas of policy.

But we must remember that the majority of United Nations Member States have not even started to use the Standard Rules, and many others need continued support and advice. We must remember that the protection of human rights for most persons with disabilities is still alarmingly weak.

That is why the work of the Special Rapporteur on Disability and the Panel of Experts on Disability of the Commission on Social Development must continue, as suggested in a draft resolution submitted by Sweden at the thirty-fifth session of the Commission.

Special contribution by Dr. Eustace Kyroussis, head of mission of *Médecins sans frontières* of Belgium

We must not forget the handicapped people of Vardenis institutions

In Vardenis, Armenia, at 2,000 m of altitude, 250 people spend their lives in a former maternity house. They are either chronic psychiatric patients or mentally or physically handicapped people. Most of them have families. Most of them could live in society, with other people, with minimal support. All of them want and can express themselves, communicate, feel, react, create, sing and dance. They need affection, and they can give affection back. Their work was displayed at an exhibition of artifacts made by handicapped people, at the library of the Department of Public Information of the United Nations Secretariat, from 3 to 10 December 1996: the exhibit featured carpets, shoes, clothes and hand-knitting.

And yet they have to live their whole lives in an environment that has very little to do with ours. Things that for us are considered as standard are not available in their house. They have to pass the rest of their lives in an old maternity home, at the outskirts of Vardenis town, that was not built to be used as a permanent habitat. They were moved there after their institution was bombarded in 1992.

Nobody has a single square centimetre of his or her own. In a room where, in the past, two mothers were happily breastfeeding their babies, for the first time now five or even more people have to spend their whole lives. Many of them still have to sleep in the old corridors. In the past a mother who had just given birth had a small cupboard in which to put her personal things for the few days that she would spend in the maternity house; the current residents do not even have such a cupboard for a whole lifetime.

In the past, a mother who had just given birth in the building did not mind if the temperature outside was -30° C, which is the case in Vardenis. The hospital was warm, and she could have a hot shower, use a clean toilet and eat proper food. Today, the patients have even forgotten about all these things. They get used to much lower standards. They cannot worry if there are modern heaters installed this year since diesel cannot be provided in sufficient quantities. Can we hope that the winter will continue to be so mild as in November 1996?

They do not worry anymore, after many years of being there, that they can have their clothes washed only once a month. It has become natural for them to have to fight for their food. Those who are aware of the situation try their best. ECHO, MSF-Belgium, OXFAM, IFRC, Genishian Fund and FAR have given help. The ministries give the help they can, within their capabilities. The directors of the institutions exhaust all opportunities to get essential things for the patients. Despite all these efforts, the patients still have many problems to face: heating, food, convenient space to live, medical follow-up, washing facilities, proper hygiene, even clothes and shoes.

The same thinking is frequently expressed by different people: Armenia has many needs; priority has to be given to "normal" people; one cannot expect the standards existing in rich countries to be applied here. But who can say these people are not "normal"? They can create beautiful things, they can serve themselves. Most of them just need a little support from other people in order to live with them. This support has been refused by their families; they were not lucky enough for that. During major crises, civilized societies first supported their weakest and most vulnerable members: mothers, children, old people. Armenian society has a long-lasting tradition to be very sensitive to these groups of people. In Vardenis, one can find all these groups. The only difference at Vardenis is that they are even more vulnerable, due to more specific needs. Eventually, they pass their life in a big building, forgetting how real life could be. The local society of "normal" people remembers them when they need workers for their fields, to be paid with a box of cigarettes.

In the meantime, hoping hat they will not be forgotten, some individuals are working to create a support structure in society for the reintegration of these people, by seeking occupational possibilities, counselling and contact with their families. Until those efforts have concrete results, the patients of Vardenis will just have to hope that at least they are not forgotten. Of the 140 patients in the psychiatric clinic, 6 died in the month of November 1996. Those who are left every month continue to scratch out a daily living in the same cold space and continue to work in the occupational facilities established in their institutions: they are making carpets, shoes, socks, sweaters and clothes for their own use, and they are painting, singing, dancing and playing — hoping not to be forgotten. What makes them different from us? Only the fact that we gave them a label "handicapped" because they need special care.

Statement by DA (Yes We Can) International Ltd.

The wheelchair of the future — today

In June 1994, 15 courageous people in wheelchairs undertook and, within five months, successfully completed a gruelling 9,000 km peace marathon through every one of the 15 countries of the former USSR.

In September 1995, five representatives of neighbouring countries successfully ascended in wheelchairs one of the highest mountains in the world — Mount Kazbek (5,047 m) — located in Georgia, former USSR. That event was dedicated to the fiftieth Anniversary of the United Nations.

Both events ran under the auspices of the United Nations "Society for All" programme, and were aimed at promoting acceptance of persons with disabilities as equal members of society.

In November 1996, a six-month 10,000 km ecological wheelchair marathon commemorating the Chernobyl nuclear tragedy was successfully concluded. Its main purpose was to heighten societal awareness of one of the main causes of disability in the Russian Federation — hazardous environmental conditions.

All these events had one thing in common that not only made them possible but also warranted their success: the wheelchairs used by the participants. The event organizers approached major wheelchair manufacturers around the world, asking them to supply their wheelchairs for the events, but only one of them, DAB International, dared to meet the challenge.

Given the fact that, on average, a wheelchair user rarely covers even 1,000 km annually, the 10,000 km marathon represented at least 10 years of rigorous use under adverse climate conditions on the rough urban and rural terrain of Russia. The average useful life of a conventional wheelchair in the developed countries is 3.5 years. Such a wheelchair is not likely to last more than a year in the much more demanding environment of a developing country. To serve the vast disabled market effectively, the Government of the Russian Federation formed DAB International, a joint venture with DA International Ltd., a United States corporation specializing in research, development and manufacture of durable medical products for developing countries. One such product developed and patented by DA is the weldless wheelchair.

The main feature of its unique design is the replacement of all welded joints with composite clamps, which eliminates the major cause of structural failure — breakage of welded joints — while providing substantially increased strength and durability. Maintenance and repairs are minimal, and can be easily performed in the field by a layman, eliminating the need for a service infrastructure. Absence of welded joints provides for high design flexibility, allowing not only easy customizing but also easy conversion from rigid to folding frame and, with optional attachments, to a lever drive, hand trike, etc. The weldless design allows the wheelchair to be assembled and customized at the regional level by the disabled, minimizing shipping and distribution costs, creating much needed employment opportunity for the disabled, and providing invaluable feedback for design improvements.

Another advantage of the design is its manufacturing efficiency. Components are fabricated utilizing a synchronized manufacturing process and local materials. As a result, a significant reduction in cost is achieved, making it possible for the disabled to acquire a strong, modern, lightweight and highly versatile wheelchair at a fraction of the cost of a comparable product.

At the present time, this wheelchair and other related rehabilitation products are being produced by DAB International at its manufacturing plant in St. Petersburg. The plant is equipped with advanced western machinery, is staffed with highly qualified personnel and has a one-shift production capacity of 50,000+ wheelchairs.

The main purpose and philosophy in creating DAB was to better the lifestyle of the disabled. This philosophy led to the establishment of close ties with the disabled community. The All-Russian Society of the Disabled, consisting of 2.5 million members — the largest in the Russian Federation and Europe — highly regards and recommends DAB products. In October 1995, they chose to exhibit exclusively DAB products at the International Rehabilitation Equipment Exhibition (REHA) at Düsseldorf, Germany. The wheelchairs received solid approval from the end-users and distributors around the world.

DA continues to work closely with the physically challenged worldwide, developing new products and improving existing ones.

Note on United Cerebral Palsy of New York City, Inc. (UCP/NYC)

A word of information about United Cerebral Palsy of New York City (UCP/NYC) is now just a click away. A new World Wide Web site, with comprehensive information about cerebral palsy, resources for families, places to volunteer and much more, has just been launched by the 50-year-old agency. This uniquely designed non-profit site would be the perfect centrepiece for an article looking at new ways that people with disabilities, their families and friends can access information and resources.

A few of the features to be found at the UCP/NYC site are:

(a) Large "hot links" and other design features to allow easy navigation;

(b) Original artwork by the people in UCP/NYC programmes;

(c) A chat room that encourages visitors to exchange information and ideas;

(d) Guest columnists, calendar of events, ways businesses can help and much more.

For more information, contact:

Ms. Kristie Afzali
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Tel.: (212) 683-6700, ext. 212

Propagation of the concept of community-based rehabilitation (CBR) in Sri Lanka

The concept of community-based rehabilitation (CBR) is not alien to the Sri Lankan society. Apart from having special institutions to handle more complicated cases, community-based rehabilitation within the family of its aged and disabled members has been practised from time immemorial in Sri Lanka according to recorded history. The ancient kings who ruled the country were also concerned about the wellbeing of the disabled. Therefore, Sri Lankan society only needs the assistance of the innovations made in this field, rather than any special training in introducing it as a completely new concept.

During 1993-1994, the then Ministry of Rehabilitation, Reconstruction and Social Welfare took an initiative in developing this concept, keeping in view the above-mentioned facts. United Nations bodies, such as UNICEF, assisted in a big way the projects launched by the Ministry. There was even a move to create a special faculty in the National Institute of Social Development to cater to the present day needs of CBR, keeping in mind the numerous new approaches made in this sphere in the rest of the world.

Consciousness of the grass-roots-level organizations and interested individuals was aroused by having training classes and appointment of local-level trainers to teach each and every household how successfully they could manage their own family members who are disabled, sparing them the experience of the loneliness and insecure conditions in institutions set apart for disabled by Governments and non-governmental organizations. Moreover, only about 2 per cent of the persons reported to be disabled were able to secure accommodation in these institutions, leaving the majority unattended. Therefore, the expansion of the services of CBR programme to divisional and village levels was hailed by those who had been neglected so far. Action was taken to improve the economic conditions of the families with such disabled members, and special legislation was also drafted to safeguard the rights and privileges of the disabled community. This programme is being carried forward by the present authorities, and its objectives are not beyond reach during the next few years in Sri Lanka, when all disabled persons will receive the warmth of their family and care of their society, and institutionalization will be needed by only a few chronic cases suffering from some kind of incurable disability.

For further information, contact:

Christie Silva
Former Secretary
Ministry of Rehabilitation, Reconstruction and Social Welfare
Sri Lanka

Note on the fourth People First International Conference (Achorage, Alaska, April 1998)

In 1973, a group of individuals with development disabilities living in Salem, Oregon, started the People First organization. These individuals quickly became known as self-advocates who would speak out and speak for themselves. Since that time, the self-advocacy movement has grown considerably, with the formation of over 500 self-advocacy groups worldwide. Because of this international movement, Self-Advocates Becoming Empowered (SABE) was founded in 1991 as the national organization seeking to unite individual self-advocacy groups to advocate for the goals of the movement at a national level.

The mission of SABE is to improve the quality of life for individuals with developmental disabilities, through:

1. Teaching individuals with development disabilities to speak out for their beliefs;
2. Learning about rights and corresponding responsibilities as citizens of the United States of America;
3. Learning how to make choices and decisions that affect their lives;
4. Seeking to obtain accessible transportation;
5. Closing institutions;
6. Ending segregation through the use of sheltered workshops;
7. Promoting inclusion practices in all schools for children with disabilities;
8. Having choices in friendships, relationships and the expression of sexuality.

People First is an internationally recognized organization for people with disabilities who believe in, practice and teach self-advocacy skills to other people with disabilities. With over 500 People First chapters in the United States, Canada and many foreign countries, people with disabilities are speaking out and speaking for themselves.

In April 1998, Anchorage, Alaska, will be the host city for the Fourth People First International Conference. The second of its kind to be held in the United States, this Conference is planned by and for people with disabilities. Some 1,000 people with disabilities from all over the world are expected to attend this three-day leadership Conference. Major programme features include workshops on self-advocacy, leadership training and promoting the rights of individuals with disabilities worldwide through the development of an international network.

Initial planning for the Conference began just after the Third People

First International Conference, which was held at Toronto. People First of Alaska was the successful bidder for the Fourth Conference. Since that time, a Conference steering committee was formed and has been raising funds, recruiting volunteer support, and developing public relations and marketing plans. Our primary goal is to ensure this Conference is planned by and for people with disabilities.

For further information contact:

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United States National Council on Disability honours Bengt Lindqvist

On 20 February 1997, the United States National Council on Disability hosted a reception in Washington D.C., to highlight the achievements of Bengt Lindqvist, Special Rapporteur on Disability of the Commission for Social Development. During the programme, Council Chairperson Marca Bristo read a letter of support from President Clinton, and presented the Special Rapporteur with a scroll noting for his dedicated service and historic contributions to ensuring equality of opportunity, full participation, independent living and economic self-sufficiency for people with disabilities worldwide. The letter from President Clinton is set out below.

> Mr. Lindqvist, through his fine work as the Special Rapporteur on Disability for the Commission for Social Development, is helping nations across the globe to understand that people with disabilities have the fundamental right to participate fully in every facet of society. His efforts underscore the importance of building communities where everyone shares the same rights and privileges.
>
> The United States of America has been very successful in reaping the benefits of a more inclusive society, but we still have much to do to fulfill our promise to citizens with disabilities. My Administration is firmly committed to continuing the vigorous implementation and enforcement of the Americans with Disabilities Act. We are equally committed to working with Mr. Lindqvist to take its message of inclusion, empowerment and independence to every country in the world. I am confident that by doing so, we can create a brighter future for us all.
>
> *(Signed) Bill Clinton*
> *President*
> *United States of America*

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