sanctions, as well as modalities for international cooperation and solidarity to allow for successful implementation. The representative also referred to the international conference on child labour which was to be convened from 27 to 30 October in Oslo by the Government of Norway, in collaboration with ILO and UNICEF. It was expected that the outcome of the conference, which would focus on international cooperation for the progressive eradication of child labour, would be useful in the preparation of the new ILO convention.

309. The representative of the NGO Group for the Rights of the Child indicated the intention of the Group to convene at the next session of the Committee an informal meeting on its ongoing cooperation with the Committee. In the area of child labour, a survey was currently underway by the NGO subgroup on child labour to collect the views of NGOs on the new ILO instrument.

### D. General discussion on the rights of children with disabilities

- 310. In the light of rule 75 of its provisional rules of procedures, the Committee on the Rights of the Child has decided periodically to devote one day of general discussion to a specific article of the Convention or to a theme in the area of the rights of the child in order to enhance understanding of the content and implications of the Convention.
- 311. At its fourteenth session, the Committee decided to devote its next day of general discussion to the issue of "The rights of children with disabilities", to be held on 6 October 1997.
- 312. In an outline prepared to guide the general discussion, the Committee stressed that throughout history children with disabilities had been, and in many societies still were denied access to education, family life, adequate health care, opportunities for play or for training, and the right to participate in "normal" childhood activities. In spite of the fact that these children were experiencing a form of social exclusion representing a denial of their basic rights as enshrined in the Convention, their plight rarely figured high on the national or international agenda, and they tended to remain invisible. The Committee also had a clear role to play in creating opportunities to highlight the obligations undertaken by Governments with respect to children with disabilities under the Convention, as well as the extent to which the rights of children with disabilities were violated. The thematic debate would mainly address the provisions of article 23 of the Convention, but would also reflect the holistic approach of the Convention, illustrating and reinforcing the interdependence and indivisibility of all the human rights of children.
- 313. The Committee identified three main issues to be considered during the day of general discussion:
  - (a) The right to life and development;
  - (b) Self-representation and full participation;
  - (c) The right of children with disabilities to inclusive education.

- 314. As for the previous thematic discussions, the Committee had invited representatives of United Nations organs, bodies and specialized agencies, and other competent bodies, including non-governmental organizations, research and academic organizations, individual experts and children, to contribute to the discussion.
- 315. Several organizations and individual experts submitted documents and other contributions on the theme. The list of these contributions is contained in annex IV.
- 316. Representatives of the following bodies and organizations participated in the day of general discussion:

#### Government bodies

Ministry for Social Protection of Togo, Permanent Mission of Aliens Appeal Board of Sweden, Permanent Mission of the Philippines to the United Nations Office at Geneva, Permanent Mission of Sweden to the United Nations Office at Geneva.

#### Regional bodies

Inter-American Children's Institute of the Organization of American States.

### United Nations entities and specialized agencies

International Labour Organization, Office of the United Nations High Commissioner for Human Rights, Office of the United Nations High Commissioner for Refugees, Special Rapporteur of the Commission for Social Development on Disability, UNAIDS, United Nations Children's Fund, United Nations Development Programme, United Nations Educational, Scientific and Cultural Organization, World Bank.

#### Non-governmental organizations

ATD-Fourth World, Childrights Research Institute, Children's Rights Office (UK), Christian Children's Fund, Defence for Children International (DCI), DCI-Benin, DCI-Colombia, DCI-Israel, DCI-Japan, DCI-Paraguay, DICAG (South Africa), Die Lebenshilfe Wien, Disabled Children Action Group South Africa, Disabled Peoples' International, Epoch Worldwide (UK), Federation for the Protection of Children's Human Rights (Japan), German National Coalition, Handicap Collectif région Annecy, Handicap International, Inclusion International, International Catholic Child Bureau, International Council of Women, International Federation of Social Workers, International Save the Children Alliance, International Service for Human Rights, Japan Federation of Bar Associations, International Society for the Prevention of Child Abuse and Neglect, Kuong Teila Graduate School of International Development, NGO Group for the Convention on the Rights of the Child, Save the Children (South Africa), Save the Children (Sweden), Save the Children (UK), Save the Children (Yugoslavia), Swedish Organization of Handicapped International Aid Foundation, Women's World Summit Foundation, World Federation of Methodist Women, Zonta International.

#### Other organizations

International Committee of the Red Cross

Mr. Bruce Adamson, Ms. Dulce P. Estrella-Gust, Mr. Sanford Fox and Mr. Vitit Muntarbhorn also participated, as did children and adults with disabilities and parents of children with disabilities. Ms. Gerison Lansdown, Director of the Children's Rights Office (UK), was designated as the Rapporteur for the day of general discussion.

317. The meeting was opened by Ms. Mason, Chairperson of the Committee, who expressed the hope that the discussion would lead to concrete action. The morning was devoted to statements by the Rapporteur of the Committee, who gave an introduction to the subject, and Mr. Bengt Lindqvist, Special Rapporteur of the Commission on Social Development on Disabilities. Representatives of various United Nations and other international agencies/bodies offered their comments and shared their experiences and views on the subject.

318. Invited speakers introduced the three previously identified sub-themes, as follows:

#### <u>Sub-theme</u>

## Right to life, survival and development

# Right to self-representation and full participation

Right to inclusive education

#### Speaker(s)

Ms. Rachel Hurst, Disabled People's International

Ms. Pearl Makutaone and Ms. Chantal Rex, two disabled young girls from South Africa

Ms. Lena Saleh, UNESCO and Ms. Sue Stubbs, Save the Children (UK)

319. Mrs. Mboi opened her introductory remarks at the afternoon session by emphasizing that in discussing the rights of children with disabilities, the main concern must always be the best interests of the whole child, not just the disability. The rights of children with disabilities were in no way confined to article 23; rather, the provisions of that article were intended to ensure that the disabled child had maximum opportunity to fulfil all the rights set out in the Convention. She pointed out that society's responsibility to protect children from disabilities must start well before birth and involved concern for all the circumstances which might result in disability at the time of birth. The challenges of protection ran throughout the life of a child and included the right to protection against violence in wartime or in peace, and protection against debilitating disease, poor nutrition and health, environmental pollution, harmful/hazardous child labour, etc. The challenge for the meeting was therefore twofold: how to protect children from becoming disabled, and how to ensure that those with disabilities were dealt with fairly, effectively and compassionately. She concluded by expressing the hope that the theme day would start a process which would lead to the development of practical guidance for Governments on strategies and policies to strengthen and accelerate movement towards

comprehensive fulfilment of all the rights set forth in the Convention by disabled children and to protection against disability both before and after birth, the construction of a set of indicators by which Governments and others could measure progress towards fulfilment of those rights.

- 320. Mr. Lindqvist pointed out some differences and the complementarity between the Convention on the Rights of the Child and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (General Assembly resolution 48/96 of 20 December 1993). The Convention he saw as an important statement of principles protecting the rights of all children, including the disabled. The Standard Rules was a whole document on disability policy, containing a much higher degree of specification giving more guidance on what should be done and how it should be done. Elaborating further the nature of "disability policy", he suggested that measures to combat exclusion and bad conditions, to be effective, must be taken in two main areas - support to the individual and measures to create accessibility. Emphasizing the importance of closer cooperation between himself and the Committee, he made seven concrete suggestions of possible areas for cooperation including various kinds of information-sharing, collaborative analysis of country reports, advocacy and public education. In closing, he urged that thought be given to finding ways to ensure active participation by disabled young people and discussion of the problems of disabled youth at a United Nations international youth forum scheduled to take place in August 1998.
- 321. The representative of the ILO spelled out in some detail child labour as a major source of disability in children and indicated some of ILO's long-standing and ongoing work directed towards the elimination of harmful and hazardous child labour. The UNICEF representative gave highlights of its programmes to advance the rights of children with disabilities. The WHO representative provided some current data and information about its work. Other representatives also commented on the issue of the rights of the disabled from the perspective of their areas of expertise.
- 322. Ms. Hurst spoke about the right to life, survival and development, citing the need to oppose with great force the abortion of unborn babies known to be handicapped and provide support as needed for the disabled child to live and develop fully in accordance with his/her rights as set forth in the Convention on the Rights of the Child. Ms. Makutaone and Ms. Rex spoke of their personal experience as handicapped young people and advocated persuasively for the right to self-representation and full participation. They presented themselves as examples of the happy outcome which was possible if disabled children were given love, care and training in appropriate surroundings. Ms. Saleh and Ms. Stubbs discussed the importance of the right to inclusive education.
- 323. In the course of the afternoon the issue of protection against disability both for the unborn and after birth was discussed from various perspectives. It was pointed out that, in the developing world, where most of the world's disabled children lived, programmes as diverse and "conventional"

such as national immunization for children, good pre-natal and birthing services for mothers, and nutritional improvement programmes must be recognized as important activities in support of children's right to development and to be protected against disability.

- 324. At the end of the discussion, Ms. Lansdown, Rapporteur for the day of discussion, presented a summary of the main issues raised during the day, as described in the following paragraphs.
- 325. The issue under discussion was not about victims or about pity, but rather about challenging oppression and discrimination; it was about disabled children experiencing widespread abuse of their fundamental human rights.
- 326. It was important that the scale of the problems experienced by disabled children be acknowledged. The statistics were shocking: huge numbers of children were disabled by the physical, social and economic world that adults had created by war, poverty, child labour, violence and abuse, environmental pollution, lack of access to health care. The world was a dangerous place for many children and adults had a responsibility to work towards the elimination of the factors which contributed to their harm. The disabilities faced by many children were not inevitable; they could and must be tackled.
- 327. The humanity behind the statistics must not be lost sight of. The contribution by the two young women from South Africa illustrated that by failing to respect their rights to inclusion and participation, the disabled are too often condemned to social isolation, loneliness, lack of friendships, denial of a voice and, indeed, often also a lack of love.
- 328. Behind the statistics and the denial of many of the rights of disabled children throughout the world lay attitudes which viewed the life of a disabled child as being of less worth, less importance and less potential than that of an able-bodied child. Those attitudes must be challenged. This required political action at every level, including legal reform to end all forms of discrimination, public education programmes, practical action to support families and communities in challenging prejudice and social exclusion, campaigns to raise awareness of the human rights of disabled children, programmes to end institutionalization of children, and positive images of disabled children in the media. It was also important to engage religious and community leaders as advocates in this process of change.
- 329. All children had the right to life. Failure to take all necessary measures to promote the survival and development of disabled children on an equal basis with other children represented a profound violation of the Convention on the Rights of the Child. All children were equal members of the human race, discriminatory laws which denied their right to life should be repealed. Public debate should take place on the unspoken assumption, underlying much medical and scientific research, that we should be striving towards the goal of perfection in human beings. It was one thing to work to eliminate impairment but quite another to eliminate the person with the impairment. We must be clear what we mean when we talk about prevention. It

was of course vitally important to work towards the creation of a safer world for children in which the risks of impairment and harm were minimized, but the solution was not through the denial of life itself as a preventive strategy. Rather, we must celebrate diversity and learn to celebrate the birth of every child, with or without disability.

- 330. There was a need to develop strategies to ensure that the rights of disabled children were respected, both as individuals and as a group. Every child should have access to the necessary medical care and treatment, to education, to help with independent living, to a wheelchair if needed. We also therefore needed to change the physical environment to promote the active inclusion of all disabled children in society. This would involve, for example, the development of accessible transport and accessible buildings shops, schools, play centres, offices.
- 331. We must take a holistic approach to disability. All the rights in the Convention must be considered in respect of disabled children, and disabled children should be considered when examining the implementation of all the rights in the Convention. That message should be applied by the Committee in its examination of States parties reports, Governments when implementing the Convention and non-governmental organizations and other agencies in promoting and monitoring implementation of the Convention. The Convention provides a framework of principles for monitoring law, policy and practice in respect of disabled children. The Standard Rules on the Equalization of Opportunities for Persons with Disabilities provided a source of detailed guidance on what should be done and how to do it. Those two documents should be used by the Committee and others as complementary tools in promoting the rights of disabled children.
- 332. Action must be taken at every level international, regional, national, local and community to effectively promote the rights of disabled children. At the international level, the Committee had a clear role to play by rigorously scrutinizing States parties reports, highlighting the situation of disabled children, and promoting the application of the Standard Rules: We could also learn from exchange of experience, research, expertise and information, and good practice between countries.
- 333. Action also needed to be taken to support the families of disabled children, promote access to education, train teachers to work in inclusive schools, enhance access to adequate health care, and provide practical help within villages and local communities. Such action would necessarily include legal reform, development of policies to promote opportunities for disabled children, reconsideration of budgets and reallocation of resources.
- 334. Disabled children, like other children, had a right to participate in decisions that affected them, but they suffered a double denial of this right. Many adults found it difficult to recognize both the right and the capacity of any child to contribute effectively to decision-making; where the child was disabled, there tended to be an even deeper inability to accept its competence. This was compounded by protectiveness on the part of carers which

sought to shield the children from the responsibility of participation. It was imperative to begin to explore ways of challenging the lack of belief in disabled children. There were many reasons for promoting more active participation in their own lives. First, decisions made about or on behalf of a child would be better informed and more likely to produce positive outcomes if the child him or herself was involved in the process. The views, experiences and knowledge of the child must be an important part of any planning or decision-making. Second, the process of participation was a central part of learning to take responsibility, to make decisions, to develop self-esteem and confidence. It was hard for any child to learn those skills if no confidence is ever placed in him or her by adults; it was profoundly more difficult for a disabled child who faced prejudice and exclusion every day of his or her life and who was constantly confronted by a self-image defined by society as negative and of little worth. It was therefore even more important that disabled children exercise their right to participate actively. Finally, by denying children the right to be heard we were denying them citizenship; they became non-people. Children whose voices were not heard or listened to were vulnerable to abuse, violence and exploitation by adults because they had no means of challenging their oppression. Disabled children were significantly more likely to suffer sexual abuse than able-bodied children, precisely because adults could act with impunity.

- 335. The inclusion of disabled children was a right, not a privilege. There was an important distinction between integration and inclusion. Policies of integration tended to seek to change the child in order to fit into the school. Inclusion, on the other hand, sought to change the school environment in order to meet the needs of the disabled child. Inclusive education needed to be introduced as part of a strategy for promoting an inclusive society. Marginalization and exclusion of disabled children were often defended on grounds of cost-effectiveness. However, such arguments could not be sustained when the question was turned around: can we afford the costs of exclusion? The loss to societies throughout the world of failure to include disabled children was huge: all their potential productive capacity was wasted. We also lost a potential for enrichment through their contribution to the social, creative, cultural and emotional dimensions of society. Inclusion was not an expensive luxury, but rather an opportunity for all children to become productive members of society. Indeed, failure to promote the inclusion of disabled children sometimes reflected less a lack of resources and more a lack of political will. It was often those Governments claiming to be least able to promote the rights of disabled children that were spending a significant proportion of the country's wealth on armaments and other military expenditures.
- 336. The final message of the discussion was that the time for talking was over. Now it was time for action.
- 337. Words of thanks to all the participants, delivered in the name of the Committee by Mrs. Karp, Vice-Chairperson of the Committee, concluded the thematic day. She said that the thematic day had proved to be not only a stimulating process that brought many new insights, but also a very moving

experience due especially to those who had shared with the participants their own personal stories and experiences. Inclusion was the goal, but it was as well a means to improve society. The aim was to have a society which accommodated a wide spectrum of individual abilities, and not a society which simply expected all to conform to one hypothetical, and often unachieved, standard of "normally". The key issue was respect for the human dignity of children with disabilities. Inclusion of children with disabilities into society was part of a process of social change to make a society in which human dignity was a living value.

- 338. On the basis of the discussions on the various issues, the following recommendations were formulated by the Chairperson of the Committee:
- (a) In its examination of States parties reports, the Committee should commit itself to highlighting the situation of disabled children and the need for concrete measures to ensure recognition of their rights, in particular the right to life, survival and development, the right to social inclusion and to participation; it should also emphasize that adequate monitoring of the situation of disabled children in all States must be undertaken and encourage moves to promote the collection of statistics and other information to enable constructive comparisons between regions and States;
- (b) The Committee should consider the possibility of drafting a general comment on disabled children;
- (c) The various bodies providing information to the Committee in the course of the reporting process should ensure that the information they provide includes disabled children;
- (d) States should review and amend laws affecting disabled children which are not compatible with the principles and provisions of the Convention, for example legislation
  - (i) Which denies disabled children an equal right to life, survival and development (including - in those States which allow abortion - discriminatory laws on abortion affecting disabled children, and discriminatory access to health services);
  - (ii) Which denies disabled children the right to education;
  - (iii) Which compulsorily segregates disabled children in separate institutions for care, treatment or education;
- (e) States should actively challenge attitudes and practices which discriminate against disabled children and deny them equal opportunities to the rights guaranteed by the Convention, including infanticide, traditional practices prejudicial to health and development, superstition, perception of disability as a tragedy;

- (f) In view of the appalling impact of armed conflict, which disables hundreds of thousands of children, States should be encouraged to ratify the Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-Personnel Mines and Their Destruction, due to be opened for signature in Ottawa in December 1997;
- (g) The Committee should promote the Standard Rules on the Equalization of Opportunities for Persons with Disabilities as being relevant for full implementation of the Convention on the Rights of the Child, and strengthen its cooperation with the Special Rapporteur on Disabilities and his panel of experts;
- (h) The Committee, in cooperation with UNESCO, UNICEF and other relevant agencies, should ensure that inclusive education is included on the agendas of meetings, conferences and seminars as an integral part of debates concerning education;
- (i) Relevant agencies should be encouraged to develop programmes which promote alternatives to institutionalization and to develop and promote strategies to deinstitutionalize children;
- (j) The rights and interests of disabled children should be included on the agenda of multi- and bilateral agencies, development agencies, donor agencies, funding organizations such as the World Bank and regional banks, as well as technical cooperation agencies;
- (k) Research into the provision of statistics and empirical evidence should be promoted with a view to: (i) promoting awareness of the extent to which the right to life of disabled children is denied; (ii) challenging the widespread existence of superstition, prejudice, social stigma and denial of access to education in relation to disabled children; (iii) challenging the argument of "cost-effectiveness" used to marginalize disabled children and evaluating the costs of exclusion and lost opportunities; (iv) bringing the issue to prominence in the process of drafting and adopting conventions on bio-ethics;
- (1) Disabled children should be consulted, involved in decision-making and given greater control over their lives; existing good practices should be publicized and shared, and appropriate training materials devised;
- (m) Governments should be encouraged to make these materials available at the community level in appropriate forms for children and disabled people; this could potentially be undertaken by one of the development agencies such as the Swedish Organization of Handicapped International Aid Foundation or Save the Children, in collaboration with some of the disabled peoples' organizations;

- (n) Training materials on promoting the participation of disabled children should be produced. The UNICEF International Child Development Centre (Innocenti Centre) should be requested to produce an edition in its series of information digests on the subject of inclusion, as its contribution to the issues raised during the general discussion.
- 339. In view of the various contributions made and the importance of the issues considered, the Committee felt that there was a need to ensure follow-up to the general discussion. It was decided to set up a working group on the rights of children with disabilities including members of the Committee, representatives of relevant United Nations bodies and agencies and non-governmental organizations of disabled people, including disabled children, to consider further the various recommendations made and elaborate a plan of action to facilitate the concrete implementation of the various proposals. The Committee decided to pursue further the question of the mandate, composition and activities of the working group at its next session in January 1998.