

Appendix 4: Presentations

Sunday 22 April 2001

**Guri Ingebrigtsen: Norwegian Minister of Social Affairs,
Opening address**

1. Introductory remarks

Dear Conference Participants, Ladies and Gentlemen,

On behalf of the Norwegian Government I am happy to welcome you all to this Global Conference, organized by the World Health Organization and hosted by the Norwegian Ministry of Health and Social Affairs.

Rethinking Care is the title of the conference — this is a challenge and a necessity, and I am certain that your contributions will be of great value for persons with disabilities as well as for governments worldwide.

You come here from countries all over the world, representing the organizations of persons with disabilities or chronic illnesses, professional organizations and various national health authorities. The six world regions of the WHO are represented here today, making it possible to give the issues and recommendations a broad relevance. It is an honour to host this important event, and it gives an extra responsibility to my government.

As you know, Norway has merely 4.5 million inhabitants. Situated at the corner of the world with the North Pole as our neighbour, we feel it is especially important to take an active part in the work of international organizations. Thus, we can learn from other countries' experiences and, in return, other countries may even have the opportunity to learn from what we have done.

This conference has been prepared by an Organizing Committee, where representatives of the WHO have worked together with the Norwegian State Council on Disability, the Norwegian Federation of Organizations of Disabled People, the Norwegian Association for the Disabled and also, I am happy to say, representatives of my ministry. In addition, several experts on disability issues have taken part in the preparation of the conference. I would like to

thank the members of the Organizing Committee for their efforts in making this conference possible.

2. The aim of the conference

As I have already mentioned, the work of this conference is important. *Rethinking care* means adopting new perspectives and, accordingly, new practices in rehabilitation and other areas important for improving the situation of people with disabilities and chronic illnesses. The subtitle *From the Perspectives of Disabled People* is of central importance because it states the basic element in 'rethinking', mainly that the equality of services should be measured from their contribution to the situation of the service users — to their possibilities for participation, inclusion and empowerment.

The results of your work here will be submitted as recommendations to the WHO. Hopefully, the outcome of these three days will be a significant contribution to ensure that the users' perspective becomes mandatory in the field of health and social policy all over the world.

3. United Nations Standard Rules and national policies

The UN *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* refer to the responsibilities of governmental bodies in evaluating and implementing national programmes that are directed at the situation of persons with disabilities.

In recent years, several Norwegian policy documents have taken the Standard Rules as their explicit or implicit frame of reference. Two White Papers deserve to be mentioned: one on rehabilitation, named *Responsibility and Empowerment*, and the other on people with disabilities, named *Participation and Equality*.

UN Standard Rule 3 concerns rehabilitation:

“States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.”

The Norwegian White Paper on rehabilitation states that rehabilitation and habilitation must be based on the rights of

individuals to define their own goals according to their own values. It also states that the services provided shall assist and stimulate the responsibilities and efforts of the individuals to gain optimal function and a sense of well-being. Rehabilitation and habilitation must refrain from focusing on diseases and producing passive patient roles. Rehabilitation and habilitation thus imply a holistic and interactive process between the users and the service providers, as the White Paper sets down:

“Rehabilitation is a process, or a set of processes, which is planned and limited in time, with well-defined goals and means; where several professions or services co-operate in assisting the individual user in his or her own efforts to achieve best possible functioning and coping capabilities, and promoting independence and participation in society.”

An approach such as this implies that the major measures in rehabilitation and habilitation must be based in the local environment of the user — close to the home and the arenas of daily life. Therefore, the local communities should play a major role in providing services that support active participation and social integration. An important objective of the White Paper is to upgrade local rehabilitation programmes, and to ensure proper coordination of relevant services. The White Paper focuses on continuity of services from specialist services in hospitals and other specialist institutions, in coordination with the services provided at the local level.

A holistic approach in rehabilitation requires both a close cooperation between professionals and a common understanding of the concept of rehabilitation and its implications in practice. Service providers often have a diversity of professional backgrounds. However, no profession ‘owns’ the problems to be solved. The user is the ‘owner’ and rehabilitation strategies must focus on his or her individual goals and needs.

Persons with disabilities will generally be the users of rehabilitation services. However, a successful policy is not only dependent on rehabilitation measures. Rather, it must imply measures on a wide range of society. Thus, the White Paper on people with disabilities has a broad focus. The White Paper states that disability:

“is based on a disproportion between the abilities of the individual and the demands from the environment and society

for functioning in areas that are more important for establishing and maintaining independent and social existence.”

A conscious understanding of the notion of disability is important because it affects attitudes, language, and the measures and solutions adopted.

The White Paper on people with disabilities is an action plan to improve society for all people, with or without disabilities. The plan describes society as having a series of conditions and demands incorporated into its structure. For example, this applies to physical access to buildings, organization of transport facilities, and access to cultural and leisure activities.

The guiding principles are ‘sector responsibility’ and ‘equal opportunities/participation for all’. This means, for example, that local authorities for the transport sector are responsible for making transport facilities available to all, or that authorities in the cultural sector must make libraries accessible to everyone demanding their services, whether they need special support or not.

The action plan for the disabled is based on the social model of disability where it is seen as a consequence of limitations in the environment. Such a model acknowledges impairment and its serious individual consequences, but does not accept it as the (sole) reason for disability. Accordingly, it is necessary to bridge the gap between the individual’s abilities and society’s demands to make full and equal participation possible for persons with disabilities.

The Ministry of Health and Social Affairs is now working on a strategy plan for habilitation and rehabilitation built on the principles and goals that the Norwegian Parliament have adopted in this field. The situation of children in need of special services will have a special focus in this plan, based on the understanding that disabled children and their families need special attention from policy-makers and health and social authorities.

Children with disabilities have the same rights as other children to live with their parents, and the parents must be given the opportunity to take care of their disabled children. In the Norwegian welfare system there are several services aimed at families with disabled children. However, sometimes it seems as if

the services have become too specialized and the service providers too numerous. For the families it can be too complicated to contact the professionals and 'get the wheels going' in their everyday life.

As Minister of Social Affairs I am looking into how we can make services more coordinated for these families. With this in mind, last month, I invited parents of disabled children and their organizations to an 'experience conference'. This provided valuable first-hand information. The statements of the parents and their organizations will be taken into account in my efforts to improve the situation for families with disabled children.

This fall, from 19 to 21 September the Government will participate in the UN Special Session for Children. In this session, as a follow-up to our national policy, I will propose *Children and Disability* as a main topic for discussion.

4. Concluding remarks

I am happy to find that a majority of the participants at this conference are persons with disabilities and parents of disabled children. It is you who are the users of health and social services and, thereby, should influence policy development and priority settings in matters that affect your lives. As I have argued earlier, increased participation from persons with disabilities is necessary to make policies better and to secure the rights and needs of the persons concerned.

The concept of 'care' is changing, from being a matter of charity to one of human rights and equal opportunities for all. This has led to a different basis for interaction between persons with disabilities and their communities. Participation will be a precondition for the restructuring of health and social programmes.

It is my hope that this conference will contribute significantly to a process of 'rethinking' that is necessary for all of us, whether we are service users, professionals or politicians.

I wish you all good luck with your important work. Thank you for your attention.

Dr Ala Alwan: Director, WHO

Your Excellency, Ladies and Gentlemen, Dear Participants,

On behalf of the WHO I welcome you all to the *Rethinking Care Conference* in Oslo. My welcome also includes personal assistants, sign language and deaf-blind sign language interpreters, as well as other resource persons who will facilitate the proceedings of this conference.

Despite the increased awareness, society's role in limiting the community participation of people with disabilities, and the increasing number of countries developing policies and legislation related to disability, there are still many disadvantaged disabled people. They do not have the opportunity to access services that can improve their functions, to achieve income-producing work, or to participate in activities of their communities. The WHO Programme on Disability and Rehabilitation aims to promote equal opportunities in family and community activities for all men, women and children with disabilities, throughout their life, by promoting equal access to health and medical care, and social and rehabilitation services that can reduce activity limitations.

The work of the programme focuses on three major components: policy development, community-based rehabilitation and strengthening rehabilitation services. The subject of our conference today is one of the major policy development activities implemented during the current biennium.

The idea of '*rethinking care* from the perspective of disabled people' was born four years ago. It started with discussions among several colleagues and partners, some of whom are present today. They include Dr Enrico Pupulin who is the coordinator of the WHO DAR Team and who unfortunately is unable to join us today as he is recovering from recent surgery, Dr Peter Mittler, and Mr Vic Finkelstein. Also included are the UN Special Rapporteur of the Commission for Social Development on Disability Mr Bengt Lindqvist (who is unable to attend today because of illness) and his panel of experts, and our two Rapporteurs, Professor Colin Barnes and Dr Ann Goerd. Those mentioned here are just a few of the people who have been involved in the discussions. Three years ago the Norwegian Association for the Disabled was approached by WHO to discuss the possibility of elaborating a joint project

proposal and becoming a partner in this project. Having agreed, the responsible programme in the WHO — the DAR Team — contacted the Norwegian Ministry of Health and Social Affairs to enquire whether they would be interested in hosting the conference. We are very grateful, Your Excellency, for the kind offer by your Government and for the establishment of a local committee, which has been highly supportive in the preparation of the conference. Allow me to join Your Excellency in expressing our gratitude and appreciation for the excellent work done by the committee. Norway is an excellent example for health and social services to disabled people.

From the very beginning it was decided that the majority of the participants in the conference should be disabled people and parents as the 'rethinking' is from their perspective. However, I am sure we all agree that it is equally important to create a dialogue between the users of health and social services, and service providers. We have invited the Presidents of major international Disabled Peoples' Organizations (DPOs) including parents organizations and also international NGOs of and for people with chronic diseases and conditions. Among the participants we have disabled 'testifiers' from grassroots level, parliamentarians, politicians, academics and service providers. The Presidents of some of the international organizations for health and social professionals having an official relationship with WHO have been invited to make contributions to this important event.

As Her Excellency stated, the objective of the *Rethinking Care Conference* is to create a forum where users and service providers can meet and discuss future strategies on making health and social services more accessible to those in need. The approach is to consider the perspective from the needs of disabled people and not what others think they need. How can disabled people be empowered to influence the decisions about their own health care, rehabilitation, support services and awareness-raising? How can professionals be trained and encouraged to listen and communicate with disabled people in need of health and social services?

I would also like to take this opportunity to stress that the conference must focus on health and social issues that are within the mandate of WHO. Health, as defined by WHO, is a state of physical, mental and social well-being and not merely the absence

of disease or infirmity. As you already know, we have limited our scope to the first four UN *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*: awareness-raising, medical care, rehabilitation, and support services. We hope that you will understand and respect this limitation, even if these issues are closely linked with those regarding education and employment, for example. The focus of WHO's efforts is on matters that will improve the health and well-being of people: health in different settings — in the family, in the community and in institutions. Tomorrow we will tackle these questions in the first working group session in the afternoon. I will not go into any details about the programme. You have all received it as part of the documentation for the conference and any changes will be announced.

This conference is a real challenge for WHO. I do not think we have ever before gathered so many competent and experienced disabled people in one single event. What is also unique about this conference is the possibility of interacting with a wide range of experts and organizations representing many areas related to the health and social services of disabled people. We know that some of the organizations represented here have an interest in expanding their future plans to work more actively in the area of disability and rehabilitation, and we hope that this conference will stimulate more interest and motivate more action and stronger networking. Let us use this opportunity to establish communications and mechanisms of work that will continue after the conference. We hope that the outcome of the conference will provide an important contribution to the work of WHO on health and social services of disabled people. We also hope that we will be able to form new partnerships, strengthen existing ones and develop a strong global network to follow up the conclusions of this conference. On behalf of WHO, I am very grateful to all of you for accepting the invitation to participate.

With the assistance of disabled people and their organizations, the Organizing Committee has made every effort to make this conference as accessible as possible. However, in spite of this, we might not have managed to create a perfect environment, so please let us know if there is anything that can be done to improve the accessibility, and the sooner the better!

Once again, I welcome you to the beautiful city of Oslo and to *Rethinking Care*. I wish you a productive and enjoyable

conference. We are excited to work with you during the next three days. We very much look forward to collaborating in order to achieve improved, more equitable and more accessible health and social services for disabled people, with special attention towards those who are in greater need.

Thank you.

Lars Ødegård: Secretary General of the Norwegian Association of the Disabled

Minister, Director, Colleagues and Friends from all over the world,

As a representative of the disability movement in Norway, and as a member of the Organizing Committee for this conference, I am both proud and happy to welcome all of you to Norway, to our capitol Oslo, and to a mutual dialogue on care, and future understanding of care, in a global perspective.

Yesterday, I was attending a conference where I was giving a speech on attitudes among and towards the disabled. When I had finished my speech a man came over to me and thanked me for what I had said. He looked at me and said, "May I ask you a personal question?" "Sure, go ahead," I replied.

"Well, I wonder what is your biggest disability?" "Oh, they are so many," I told him. This he could understand, but he asked, "What are your major problems?" "Well, I reckon steps, narrow doors, toilets, buses, and..." I started to say.

Before I could finish he interrupted by saying, "No, you don't understand me. I wonder what is your handicap?" "Well," I said again, "my surroundings — and sometimes the attitudes that I meet from others — they are my major problems."

I realized that I had not fulfilled his expectations. Once again he told me that I did not understand his question, saying, "What I really wonder is how is it to live a life with your body? I mean, just by looking at you, in your wheelchair, I understand that your life cannot be simple at all."

Thus, I realized that I had to explain that my body is not my problem. So I told him, "I am my body, my body is me! I cannot consider my body as my problem. If I did, then I also have to put the blame on myself. And it is not me or my body's fault that I am excluded from equal participation. My body cannot be the cause of the discrimination that I have to face. If I thought so, then I could not have any self-respect and my life would be pure misery. Regardless of my sex, regardless of the colour of my skin, regardless of the shape of my body — I don't accept myself as the problem!"

You may think this man lacked any relation to people with disabilities. But you would be wrong. This man was disabled himself! He was as institutionalized psychologically as many of us are — because we are victims of society's way of thinking about us — both as individuals and as a group.

This story is one reason why I have a strong hope that these days ahead will be a lot more than just testifying and talking about our experiences with the care service, and how it is practised around the world. Our challenge is not primarily to share what we already have been thinking.

In my opinion, the biggest challenge for us all here in Oslo is to think again — to rethink, to think new thoughts, and to dare to ask ourselves the fundamental question: *Are my ideas and understanding according to the real challenges for the future development of care?* Is my understanding of my job as a caregiver, as a politician, as a scientist, as I would want it for myself if I am ever in need of someone's care? Is my understanding of myself, as a disabled person, according to the ideas based on the human rights for independence, dignity and equality?

It is difficult — and indeed challenging — to take a critical look at your own views. Do I have more to learn, do I dare to look at it from another perspective, and do I dare to turn established facts upside down? Thus, it might help to remember these words from a great Danish philosopher, Søren Kierkegaard:

“To dare is to lose your foothold for a moment — not to dare is to lose oneself.”

A society without care is unthinkable. We all need care, at the beginning our life, at the end, and sometimes in between. Many people need more — for a shorter period or permanently.

In any society, people are interdependent, and this interdependence is a reason for forming families, groups, nations and global structures such as the UN and the WHO.

Care is a basic value in human society. However, for many reasons, the care given does not often empower people. It may even be the inverse — it may increase the helplessness and loss

of value. This is certainly not intended by anyone. What can we do about it? This is a major issue for the conference.

This conference is an indication of the need for rethinking, the need for finding strategies to achieve more enabling care. We should confront our norms and practices — the norms and practices shared by those giving and receiving care. There is a possible joint benefit in making a change — disabled persons who are in control of their lives are less likely to become a burden, and are more likely to be able to participate. But still, there is a long way to go!

Despite the fact that it is the year 2001, we live in a time of myths and prejudices, and they still breed well! For example, the myth that we cannot make the world a better place or a world with equal opportunities for all. Prejudices can undermine sustainable development and relations between people, and thus undermine care. On the contrary, prejudices can promote a development where the rich are getting richer and the poor are getting poorer.

The *most* serious threat against care, social development and human interrelations is implied in the sayings that are heard more frequently these days:

- “I don’t care!”
- “If it isn’t my life that is at stake, then it’s none of my business.”
- “The discrimination going on is not my personal fault, so it is not my responsibility.”

We are indifferent — too many of us do not care! Indifference never leads to understanding. Lack of understanding creates lack of involvement. Human beings live in poverty, in desolation, without dignity, and without self-respect owing to lack of involvement. It is a vicious circle and it must end.

How can we break it? By doing to others what we ourselves find best? By providing care to others based on our own rules? By making others live the way we want them to live? Such a strategy does not break the vicious circle — it just gives it another dimension.

Using our personal norms as guidance for our care for other peoples’ rights, freedom, and self-respect does not take into account the needs of the other person, but rather our own needs.

This is how prejudice is created and prevails. In spite of differences in culture and traditions, in spite of very different welfare systems and economic standards, and in spite of the enormous differences between nations, the disabled and others in need of assistance to live an independent life meet the same myths and prejudices all over the world.

Most often the myths and prejudices are based on the perception that impairment is the same as disease and suffering, and therefore they are not compatible with concepts such as empowerment, independence, self-reliance, and self-respect. Such prejudices are the most serious threat against our quality of life because it is myths like these that make us the *objects* for the indifference or misunderstood care from others. We become forgotten and unrecognized. They do not promote integration — they segregate and discriminate.

How do these prejudices and attitudes about disability and the lives of disabled people evolve? Today we know many of the causes of impairments. We are familiar with more of the genetic codes, with the consequences of pollution, and we are in the process of solving the puzzle of life itself. We are solidly anchored in a highly sophisticated scientific tradition, but the myths and the attitudes persist. They may appear slightly different, but they are as viable as ever.

Modern knowledge alone has proved to be insufficient to make a difference because knowledge itself is worthless if it is not connected to a real understanding. This kind of understanding cannot be achieved through books alone — this is something we must seek within ourselves. Regardless of level of education, we may not really understand. We have learnt about polio, but very little about living with polio. We can, through medical intervention, cure more diseases and know their pathology. Regardless of this we are poorly equipped to understand that disability first and foremost is not a physiological or pathological phenomenon, but a sociological one that is community related.

The present care system of mobilizing when impairment occurs has been dominated by the perspective of pathology, and on top spiced with a good share of paternalism. Health personnel have been educated in a medical tradition where cure is the optimal

goal. With such a goal, most of us that have permanent impairments will remain losers.

Rethinking care does not primarily mean rethinking medicine, rethinking professional methods or treatment. *Rethinking care* is a matter of rethinking attitudes — attitudes towards other people and rethinking the possibilities for the disabled to become independent and equal.

There are many important aspects to be discussed concerning care. One important discussion within the Organizing Committee has been whether the perspective for the conference should be technical and medical quality of care, or attitudes within ‘the care business’. We agreed that the most basic issue to promote productive care is attitude. This is a global issue, regardless of the economic or technological level of individual nations. Another important decision has been to bring all stakeholders together to discuss all relevant angles and perspectives.

This conference has great potential for the disabled to fight for equal rights, for professionals to strive to provide useful and empowering services, and for politicians who must take into account budgets and the welfare of the population. You are a carefully selected group.

On behalf of the Organizing Committee I would very much like to express our gratitude to WHO for their initiative which made this conference a reality. I also thank the Norwegian Government for their role in hosting this event. Through the dialogue here in Oslo, we will all have the opportunity to influence WHO’s future strategies. We can help WHO to build a stronger and even more sustainable involvement regarding care and policies towards the disabled.

The Organizing Committee would have liked to see even more participants than are present today. We would like many more to shape the way forward. The world is full of need for an increased awareness and effort concerning care that can create a sequence to promote equality, empowerment and dignity for all people who are in need of assistance. Despite the fact that we are few, there will be thousands worldwide waiting for us to develop new thoughts and ideas. They will help us to spread the ideas all over

the world so that they can grow and be transferred into new practices that will indicate a shift of paradigm.

The members of the Organizing Committee would like to thank all those who have contributed to this conference. People from all over the world have presented inspiring papers, and much assistance has been given to make this conference a fruitful one that will hopefully inspire you all to keep up your good work and to create new ideas and solutions. We would especially like to thank Colin Barnes for his assistance. Through his ideas, his excellent work and contributions we feel that the days ahead may fulfil our hope for a successful conference.

Together we have tried to prepare a forum for you, for a three-day process of highlighting experiences and constraints, for identification not of all needs and constraints, but a few of the most important ones, and for giving a direction and a strategy for the future. We wish you a pleasant stay and hope that we can establish good and long-lasting relationships.

Now, at the end of this speech, let me again quote Søren Kierkegaard on his ideas about care:

“In order to assist someone, I need to comprehend more than he does — but first of all to understand what he understands. If I should be unable to do so, then my greater ability and knowledge would be to no avail. If I still insist on demonstrating my abilities, it is because I am vain and proud and in reality would like to be admired by the other — instead of helping him. All genuine assistance starts with humbleness towards the person I want to assist, and therefore I must understand that the act of assisting others cannot be based on the will to rule, but on the will to serve. If I am unable to do this, then I cannot help anyone either.”

Thank you for your attention.