



REPORT

SEMINAR

*YOUNG PEOPLE WITH A
PHYSICAL DISABILITY*

Friday 7th of MAY 1999

Training centre Guislain
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Foreword

These last years, all over the world, more and more attention has been given to the theme of human rights. After an interest for women's rights during the seventies, the rights of children and of persons with disabilities have been stressed during the eighties and the nineties. Under the impetus of the UN, 1981 became the year of Persons with Disabilities, and in 1989, the UN adopted the Convention of the Children's Rights (see further in this file). In 1994 came the approval of the UN Standard Rules for Equal Opportunities for Persons with Disabilities, a document containing 22 guidelines promoting the integration of disabled persons in different aspects of life.

This is the theory, but how is daily practice? During the discussion day "Young People With a Physical Disability", we looked shortly into the theoretical part and then went on to the concrete experiences of youngsters from North and South. This happened in a debate where youngsters presented their opinion and in workshops where in view of playful techniques the broached themes were looked at in more depth.

It was an instructive day.

Programme

- 09.00u: Reception**
- 09.20u: Word of Welcome**
Mr. Pierre Mertens - chairman PHOS
- 09.30u: The Rights of Children: a task for everybody.**
Ms. Mia Versmissen – Training Responsible Unicef Belgium
- 09.50u: Young people with a physical disability, a world wide view.**
Mr. Darryl Cowley - Human Rights for Disabled Children - UK
- 10.15u: Coffee break**
- 10.30u: Debate: Living with a disability.**
*Youngsters from North and South exchange experiences. The international guests are: Nimal Jayawardene from Sri Lanka
Idriisa Kiragga from Uganda
Ani Zaharia from Romenia*
- 12.00u: Lunch**
- 13.30u: Workshop as desired.**
 - *Informative game with discussion.*
 - *Game with photographs and discussion*
 - *Movie with discussion.*
- 14.45u: Coffee break.**
- 15.00u: Discussion group as desired.**
 - *Getting to know the foreign guests better.*
 - *Exchange about projects regarding children with a disability.*
- 16.00u: Word and drink to close the day.**

WORDS OF WELCOME

Pierre Mertens, Chairman of PHOS

Welcome to the theme day: "Young Persons With a Physical Disability".

A child born with a physical disability is confronted, from the beginning on, with obstacles. From the start, more attention is given to what is wrong than to what is positively possible.

Parents receive a special child that is craving to be approached in a normal way. The child grows up with a body that is different. With some luck, at home, in a normal school, in a normal youth movement.

Young persons with a physical disability bear a whole history with them. Their "being different" has also given them another life. It has strengthened them or it has marked them.

Many young people are tired of being provided with medical care. They throw their appliances in a corner of the room and prefer to sit in their wheelchair and try to pick up something that is worth experiencing on this clod of earth.

Living is friendship, is experiencing something, is enjoying, is being somebody, and therefore no operations exist. How do they experience this, young persons with a physical disability? How do they consider the world that created special places for them? What are their rights? How do they themselves consider their duties? What keeps them busy? How do they see their future?

What does it mean now, to be young with a physical disability in a developing country? How does their situation differ from ours and what are the similarities?

We want to examine today's issues in relation to the Children's Rights. Today we listen to young persons from North and South, young people with a physical disability.

This afternoon you'll have the opportunity to participate in workshops and discussion groups.

CHILDREN'S RIGHTS: A TASK FOR EVERYBODY

Mia Versmissen – Responsible Training UNICEF Belgium

At the end of 1989, the UN adopted the Treaty on Children's Rights. The acceptance of the text of this Treaty by the international community may indeed be called a historical event. The Treaty on Children's Rights is legally binding for countries that signed it.

It also covers all aspects of children's lives. The authors of the Treaty did not hesitate to include children's rights for participation. Children are, according to the Treaty, fully-fledged citizens. For this mere reason the Treaty on Children's Rights is a revolutionary event.

A legally binding Treaty on Children's Rights.

After the unanimous adoption of the Treaty on Children's Rights on November 20th 1989 by the UN's General Assembly, the first ratifications followed quickly. Today, almost all countries have signed the Treaty. As such, it has become the universally accepted minimum standard that has to be guaranteed for all the children of the world. The rapid and almost universal signing makes the Treaty a unique event in the rich history of Human Rights.

The Treaty on Children's Rights is legally binding for the countries, which ratified it. It imposes obligations on the signing states. They have to take measures for the practical respect of the rights of children in their country. That is no easy task. The area of application of the Treaty is quite large, so that it obliges signing states to keep the perspective of children's rights in mind for every decision. The importance of the problems facing the world's children, and the misery in which they often have to survive, stand in a sharp contrast with the meagre (financial) means certain countries have at their disposal.

That's why the Treaty on Children's Rights stimulates international co-operation and solidarity, and stresses a gradual and progressive approach of the problems facing children, so as to reach more respect for the rights of children. The spirit of the Treaty is one of stimulation, not punishment or hinting at states that cannot observe their obligations immediately. In other words, the Treaty prefers a practical approach instead of a dogmatic one.

In view of implementation, the Treaty has set up a Committee for Children's Rights. This committee is made up of ten independent internationally respected experts in Children's Rights. It analyses the reports presented every five years by the signing states, in which they report on the measures that have been taken to rectify the existing violations of children's rights and about the difficulties they are experiencing. The Committee makes remarks and proposals on the policy that should be pursued to contribute to a greater respect for children's rights. The duty of every signing state to report, contributes to an increased attention towards children's rights and could initiate a particularly large and useful social debate on the place of children in society.

A comprehensive text on children's rights.

The Treaty on Children's Rights treats all aspects of children's lives. This Treaty is without any doubt the most comprehensive text concerning human rights.

The usual distinction between civil and political rights on the one hand, and social, economical and cultural rights on the other, disappears in the Treaty on Children's Rights. By letting all these rights appear in one text of the same treaty, the Treaty on Children's Rights makes it clear that all these rights are inextricably linked with one another. Thus the Treaty wants to make it clear that no one right has a priority over another. In addition, the authors of the Treaty have made a text, which can be used, not only to fight the violations of children's rights, but first to promote these same rights.

The Treaty contains a preamble and 54 articles. A number of principles count as key concepts for the Treaty. Article 3 introduces the concept of "the interest of the child" that has to receive priority over all decisions taken regarding children. The Treaty puts the non-discrimination principle first (art. 2): all rights apply to every child, irrespective of "race, skin colour, sex, language, religion, political or other convictions, national, ethnical or social origin, fortune, disability, birth or another circumstance of the child, or one parent or legal guardian". The principle of non-discrimination also means that the stipulations of the Treaty must apply to all children on earth, wherever they live. Article 6 stipulates that the survival and development of each child must be ensured, together with article 4, which quotes the principle of international solidarity. Another key concept of the Treaty is each child's right to have his/her own opinion (art.12) and the right of active social participation (cf. *infra*).

The principle of mutual solidarity between the rights written in the Treaty renders any division of the Treaty artificial. Still, such divisions offer the opportunity of an easier exploration and understanding of the Treaty.

Beside the classic divisions into civil, political, economical, social and cultural rights, one often follows the "3 P's division that refers to: Provision, Protection and Participation:

1: "Provision" refers to the rights guaranteeing services to children, e.g: feeding and health care (art.6 and 24) and the right for education (art. 28 and 29);

2: "Protection" refers to the rights that must protect the child against exploitation and ill-treatment; e.g: right of physical integrity and protection against exploitation (a.o: art.31 *ea.*);

3: "Participation" concerns children's rights guaranteeing a participation of the children in social life, e.g.: freedom of thought, of expression and of assembly (art. 13 up to and including 17).

Participation

The right of participation is, as we have said, one of the key concepts of the Treaty on Children's Rights. This Treaty is the first text on children's rights containing rights of participation.

By including the rights of (social) participation in the text of the Treaty, one recognises that children are capable of participating actively in social life. The Treaty on Children's Rights recognises the child as a fully-fledged citizen whose human dignity must be respected and who has to be able to participate in a positive way to the construction of society. Children have to express themselves freely. One has to listen to them. For the time being, children constitute all too often a social group, which doesn't get a chance.

The principle of participation runs as a red thread through the Treaty. Art.12 puts the right of a child to participate in all matters concerning him/her (cf.infra). It has thus to be applied and respected in all aspects of children's lives: education, health care, local community, policy, family etc. Naturally, the principles of non-discrimination and universality apply also here to all children.

The right to participate is explicitly mentioned in different articles of the Treaty on Children's Rights.

The rights of (social) participation of children registered in the Treaty gave a world-wide impetus to changes in laws and regulations, the organisation of inquiry, the adaptation of the living environment of children, the organisation of playful activities, etc.

Thus in Belgium, in 1995 a new law has been voted, giving children the right, in all procedures involving them (e.g.: divorce), to be heard by the judge. Playgrounds built in close consultation with children are growing like mushrooms. Children's community councils also are increasingly successful. In Mexico, the 1997 presidential elections were accompanied by an inquiry towards children about their problems and priorities.

So, as you can see, slowly but surely, children's rights of participation take hold in their daily lives.

Young people with a disability: a world-wide view.

Dhr. Darryl Cowley - Human Rights for Disabled Children

What I want to say briefly is about some of the issues, which make human rights of the disabled children probably the most urgent and important issue of human rights in the world. And I want to say something about some project we're developing in *Disability Awareness in Action*, which is called *Rights for the Disabled Children* of which I'm the co-ordinator. It is a working group, looking to advice the Committee on the Rights of the Child.

I start with a very short quote from a young man, called Michael Z.: " My polio was a devastation to my mother, since society at the time thought it was a bare, a curse by God."

That's why there are the negative statistics about disabled children, that's why disabled people are the poorest of the poor in every country in the world. It is probably the attitude towards disabled children and disabled people which are the cause of many shocking statistics, denying far too many children the right to life and development. So, many of the economic arguments are often quoted as an excuse for these attitudes and the policies derived from them are themselves based on these negative attitudes and not on long term financial sustainability and human rights.

Disability is a human right. All the articles in the Convention on the Rights of the Child are applicable to the disabled. It is essential to draw attention to what Perres Decuellar called : the silent emergency.

There are a number of stories from across the world that show that disabled children have very few rights. But there are also examples of people who have come beyond the negative attitude. For example: Ed Roberts, a founder of the Independent Living Movement in the USA, written off as a vegetable at 15, his mother was told to abandon him, luckily she took no notice. Joshua Malinga, who is the president of Disabled People International and the ex-mayor of Bulawayo in Zimbabwe spent his first twelve years of life crawling around the floor of his mothers' hut, uneducated and isolated until he was rescued by a missionary.

Disabled girls have an even worse time. Sometimes they survive despite the efforts of their families to starve them to death. I was bewildered by a lady called Vandana, in India: "After I got my polio, my mother refused to see me, I managed to keep myself alive by scavenging for food and stealing from my brothers. I never went to school but was taught to read and write by one of my neighbours."

There are other situations where the mother of a disabled child gets abandoned by her husband, he can not tolerate the stigma attached to having a disabled child or is not prepared to take on the extra responsibility. In developing countries, this situation often forces a mother either to abandon her child or to become a beggar.

It seems to become clear that the very negative angle within attitudes on disability leads to inappropriate evaluations of the quality of life with a disabled child. The life of

a disabled person is so obviously one which is a burden to himself. The families and the state often act like it never occurred. These attitudes may appear to stem from kindness and consideration, but in reality this kindness and consideration is often based on the non-disabled persons' fears of what it is like to be disabled. No proper consideration is given to ensure that a disabled person, child or baby, has the right to evaluate their own life. Neither is there a consideration of the role of disabled within society, the nature of their differences and the acknowledgement that their differences should be celebrated and not denied.

These stigmas and attitudes have also had an impact on policies and legislation, regarding abortion, sterilisation and genetic engineering, euthanasia and other bio-ethical issues. In many countries across Europe, termination is normally allowed up until the 22nd or 24th week. If the foetus is believed to be disabled, it can happen anytime up until birth. This completely different legal basis denies the disabled foetus the same right as a non-disabled foetus. Adding to which many mothers are put under considerable pressure to have the diagnosis of impairment and if it proves that they are positive, they are put under even more pressure to have an abortion.

Probably one of the main excuses of governments, local authorities and other providers for not ensuring an implementation of comprehensive non-discriminatory measures for disabled people, is its cost factor. These costs are generally out of proportion, this is why human rights attitude towards disability are not taken into account. Traditionally, most of the money spent on disability services went into buildings, for special schools and institutions, expensive professionals, rather than into local based initiatives. The solution to these expenses should not be to cut costs, but to put the funding towards training disabled people and supporting disabled people's rights and so lead to their full involvement into society. There is a perfect example of this in India where the school "School for Divine Light", a trust in India which for 45 years educated blind children, was taking in only ten to eighteen people each year. Only 5 % of the children in India were being educated in schools for the blind. Then there was a radical change. Without increasing the budget and by becoming a resource centre, training teachers in mainstream schools became a way to integrate blind children into these schools. This centre now reaches virtually the whole of India and provides training to enable children with other impairments to go to mainstream schools.

For all the countries in the world the most important asset is their people. Sustainable development depends on the involvement of all people and children are the future leaders and the future economists of their countries. It does not make economic sense to leave disabled people out of the equation once they make up 8 to 15 % of the population.

So one of the reasons for focus on abstract notions of costs in relation to disabled people and for stigmatising life threatening attitudes is that disability is still seen as an individual characteristic and not the social situation that it really is. The Convention of the Rights of the Child upholds the right to life and development for all children: girls, babies or stepchildren and children who work. This is well known and documented. The issue of child abuse is becoming every day news, these wrongs need the

world's attention and something has to be done about them. But the world also has to pay attention to the denial of life and the development of the disabled children. And this brings me to the next brief issue that I would like to talk about: a working group that we have set up to look at the rights of disabled children in conjunction with the Committee on the Rights of the Child.

In 1997, following the suggestion through a number of international NGO's, the UN Committee on the Rights of the Child held a general discussion day on the rights of disabled children. And they put forward a number of key issues and 14 recommendations to take forward the rights. One of these recommendations was that a working group be set up to look at the rights of disabled children and to advise the Committee. Then after some time, in 1998, it was hoped that the UN would set the working group up, but their lack of resources didn't enable them to do this. So, D.D.A. raised money to fund some meetings and to appoint a co-ordinator for a working group. Now, this working group consists of a number of INGO's, a member of the Committee on the Rights of the Child and Mr. Bengt Lindqvist who is the Special Reporter of the Rights of Disabled Children of the UN. The working group is called Rights of Disabled Children and had its first meeting in March this year. A number of points of action took us forward. The main one is to advise the Committee and its work with state parties, so that it is not just looking at the rights of children, but specifically targeted at the rights of disabled children.

The Committee has admitted that their awareness of the rights of disabled children is somewhat limited and they're looking to us for advising on questions to our state parties, for looking at the violation of the rights of the children and to have an input to such things as the pre-sessional meetings. We also hope to advise the Committee in respect of the 2001 Children's summit. One of our main hopes is there will be an input on that by the disabled children themselves, so it is very clear that it is the children's day.

We also want to draft a general comment to include a statement on bio-ethics, which is an increasingly bargaining issue, especially in Europe with the growth of gene-project and the option to have the so called designer babies. We have to have meetings with the UN-agencies and to look at what they are doing to enhance the rights of the disabled children. We shall hold a number a regional meetings in Latin America, Africa, Asia and Eastern Europe and this again will create opportunities for younger people to come together to express their concerns and their hopes of what they want to change in the future. And create opportunities for children to have a voice and to feedback information to the Committee. We want to create opportunities for people to come together and work with those most knowledgeable about disabled children in their regions and to promote disabled children's rights.

Those who will be involved will not be experts in the usual sense of the word, they will be people who usually do groundwork with children, they will be the children themselves and maybe representatives of some of the UN-agencies. But the emphasis will be on a pragmatic approach. We further want to get the regions involved in the 2001 summit, so that each region may have a delegation of children.

The initial programme of the working group is due to run until 2001, that is not very long and I'm sure they will have to go beyond that. The work is reported regularly in

D.A.A. newsletter which I expect a number of you get and if you want to keep in touch then ask to get on the mailing list. We aim for as many organisations and individuals to take part in this working group as possible and to spread the word about what we're doing. So, if you would like to be kept informed, either contact me or contact D.A.A. in the U.K. I hope that the work we're doing will have a significant impact on disabled children's rights across the world.

And also briefly, there is also another working group which is looking specifically on the rights of disabled children in Europe. It has a similar mandate to that of the international group. Thank you.

Debate : Living with a disability.

After the speakers drew a general picture of the situation and the rights of people with a disability all over the world, young persons from North and South give their own view of the world in which they're living.

The participants to this panel were:

- Nimal Jayawardene, accompanied by Mrs. Sunethra from Sri Lanka
- Idriisa Kiraga from Uganda
- Ani Zaharia from Romania (who came later due to a strike on Air France).

Nine pupils of a Special Institute (Sint-Lodewijk) in Wetteren and three students from the Ghent region -all of them disabled persons- had also been invited to participate actively in the debate.

From what precedes, we know that disabled persons have rights based on International Conventions, but during the speech given by Darryl Cowley, it became clear that the concrete interpretation was not so brilliant. Worldwide, efforts are made to do something about it, as e.g. the announced summit in 2001, but it certainly promises to be a hard struggle.

The right to participate and to have one's own opinion, as well as to voice that opinion, are important rights. This debate stems from there: to interpret opinions and exchange experiences about three questions/themes:

1. What do I have at my disposal, what choices can I make? Where am I dependent on others, and where can I make my own choices?
2. How important is it to have one's own income?
3. How important is it, as a disabled person, to want and to have children?

We are going to make a comparison concerning these three questions, between the situations in Belgium and in the countries of our foreign guests. The moderator's comments are printed in bold.

1. What do I have at my disposal, what choices can I make? Where am I dependent on others?

A disabled person in a housing project once said: "I live quite normally, you know. The only thing that annoys me is that I always have to ask for help, this dependence is often heavy. For the rest, I function in a perfectly normal way."

Idriisa (Uganda): It's important that we can share ideas and experiences. I'd like to introduce myself briefly. I'm Idriisa from Uganda, I'm 23 years old. I was born with a genetic deviation to my left arm and left foot. I haven't studied much, due to the negative attitude of my parents. My mother died when I was only fourteen and my father decided not to pay any more for my education. To survive I had to scrape some food together. Being lame, I was considered as someone who was unable to care for himself. In developing countries, there's a big chance for persons with a disability to die as a consequence of secondary problems.

In Uganda, we, the disabled, do our best to be independent while the people in general have a negative attitude towards us: they give us the cold shoulder and discriminate against us. Some disabled persons have studied, but they do not want to give us work. We can do nothing else but beg in the streets. That's why we have to fight for it ourselves. We start projects where disabled persons can begin to work.

Nimal from Sri-Lanka (Mrs. Sunethra mostly speaks for him while Nimal does not master the english language): The situation in Sri Lanka is similar to the one in Uganda. If you're born with a disability, you're condemned to become a beggar. To be(come) independent in a country where poverty is number one, is already a big problem. Add to this that the community does not want to accept disabled persons. To give some examples: in the countryside, one doesn't want to see a person with a disability early in the morning while this brings bad luck. When they see someone with a disability, they turn back and run away, cursing. Also in the surrounding area of the institution for disabled persons -Suhada- which I'm running, the land is worthless for the sole reason that one can see disabled people there, early in the morning. That's the kind of mentality we have to face.

Nimal has a bone disease whereby a mere shock causes his bones to break, even firework can cause his bones to break. In Sri Lanka today, he is more or less the only one to be heard or seen because he's very popular. He never went to school but now he follows a course at the Open University, mainly thanks to the support of the Suhada Rehabilitation Centre, a centre that is concerned about disabled persons without parents. He was born in a rich family but his parents always hid him. They did not want to tell anyone they had a disabled child. He stayed at his grandmothers' home. Even when he'd obtained a wheelchair through Suhada, he was not allowed to move freely at home. So, there was no other choice than to admit him in the institution. His family was very angry that I had admitted him and tried to teach him to read and write. Something he was already busy doing by himself. He hid under the bed and taught himself to read and write. Now he doesn't live in the institution any more, he works sometimes as a journalist and has set up an organisation with social purposes, the Shanti Seva Foundation. He travels on his own to the countryside, looking for war victims. Because of his popularity, he's now accepted by his parents.

But he is an exception. In general, persons with a disability live in quite miserable conditions. There are no schools for physically disabled people, though there are some schools for deaf and blind persons. For the mentally disabled there are one or two private schools which are prohibitive for the poor population. And it was quite a struggle to allow them to go to ordinary schools. There was always a good reason not to accept them: too old, no birth-certificate etc. Now schools have to admit children with a disability, without birth-certificate and without age limit. Also because

the war causes an important increase in the number of persons with disabilities. At this moment, ten percent of the population is disabled, and most of them are left behind.

When listening to Idriisa and Nimal, we hear, on the one hand quite a lot of discrimination and, on the other hand a strong wish to be independent, to be able to make one's own choices. They try this through a very personal battle. What about the wish to make one's own choices here?

Nick (a MPI student): In this society it is apparently the mentality to think: "Poor thing, he's disabled, we must be cautious of what we say because he could be hurt very quickly." But this is not the case for most of them. The able-bodied persons should go about persons with a disability just as they do between themselves. And that is, I think, the biggest problem here and in other countries. An example: I live in Leuven and I wanted to go to Ghent by train. My mother only allowed me to do that if somebody could come and pick me up at the station, while I know perfectly well from school that I can do that on my own. And it's not only my mother who reacts like that.

So you want to make a number of choices completely by yourself and manage on your own, and you stand up against the mentality to put the disabled people in a cocoon, to handle with too much caution and thus depriving them of chances to do things independently.

Katty (blind student higher education): First a reaction on what the foreign people told us. When I compare with our situations, I realize we live in an enormous luxury. We have to realize that. They are even more dependent on institutions and on the goodwill of the society. We are not condemned to become beggars any more. We get a chance for education, there are enough schools which can train us, and then it's up to us and to the school's staff to guide us in that matter. But it's especially up to us to go that far, even if the cocoon mentality still continues to exist.

Concerning dependence, what causes me the biggest problems is when I need to consult some documents for my training -I'm studying history- I cannot go to a library and ask: "I want to read that book". For me, documents and books have to be made legible. But also for mere ad hoc decisions as e.g. a visit to a friend in Leiden (Netherlands), I have to undertake plenty of steps to arrive there. But still, these remain pure luxury problems that we have to face, while our foreign guests have to fight with much more fundamental problems. It's a shame, really, to have to mention that kind of examples.

An (MPI student): I fully agree with Katty. We have luxury problems compared to our foreign participants. But first something about the cocoon: many disabled persons put themselves in a cocoon, they say nobody's looking after them. Concerning my own situation: I could follow a normal education up to the fourth year of high school, but for reasons of physical problems I had to step over to special education, and there, I must say, I've had to open my eyes. I don't say I'm a disabled person, I'm a person with a disability. I'm a young person as anybody else but, incidentally, I have a disability. I'm quite independent, at home we are four children and I'm quite simply one of them, I do the dishes, I tidy up my room, I clean up my table, etc. as far as it is possible. There are a number of problems though, I'm sitting in an electric

wheelchair. It is not very easy to go on the train just like that. Therefore you need to phone (I also do that myself). In Brussels and in Ghent, that's no problem while there, they have a trailer to load you on the train, but in Waregem, where I'm living, they don't. They have to put me on the train with my electric wheelchair, they've forced the back of my wheelchair and their own backs as well, and that is a problem, isn't it? So, yes I'm independent, but still, one often has to hear that it doesn't work after all for reasons of infrastructures.

What can you do about it?

I forced my will through in Waregem. They have put me on it. I could also have found someone to drive me, but I did not want that. Now I've heard that there will indeed be a trailer after all.

Herman (a project co-ordinator): A reaction on the Belgian speakers. Here, we have luxury problems, in comparison with countries with much less economical possibilities, yes. When we compare ourselves with other people living in this society, then we have much less chances, then we're also strongly discriminated against. Look at education: it's still only a small minority of people with a disability that is following higher education. Plenty of them attend, unnecessarily, schools for special education where they do not get the same opportunities, that often are not located in their neighbourhood and are mostly boarding schools. There are plenty of examples. The fact that we have an easier access to aids does not mean that we get the best aids.

One of the first problems mentioned by the hosts is that of neglect. This problem also exists here. It is exceptional that a disabled child would be so neglected that it would die, or that the disability would worsen, but it often happens that a child with a disability is not welcome in a family and that it is left in a boarding school. Even if the child is then in the hands of professionals with the appropriate means for care, it still misses plenty of motivation that can come from a normal family, it misses the human warmth of a family. That is also neglect.

Ariane (student in higher education): What I'm still a bit missing in this debate is that when you try to be as independent as possible, to choose your own study matters and to live independently in your own flat, and that you manage to care for yourself for a whole week, then one often hears the comment that you're left to your own devices. People wonder why this is, it seems to become quite complicated when disabled persons are beginning to care for themselves.

This is being confirmed once again by Katty with an example of her social environment.

What do the foreign guests think of this?

Nimal: In Sri Lanka, even the roads are lacking, even for normal people of the countryside it is difficult to go to school, even more so for disabled people. There are no toilets and no transport. If we compare the situation here with the one in Sri Lanka, it's like heaven and hell. We've been to the Reva exhibition in Ghent (i.e. an exhibition of all kinds of technical aids compensating physical and sensorial

impairments) and we couldn't believe what we were seeing. Everybody can be glad to be born here, even with a disability, there's so much difference.

Idriisa: There are 20 million people in Uganda, of which 4 million are disabled. They have all kinds of impairments: deaf, blind, mentally retarded... and these people have a big problem: there are but a few schools for them. Sign language is not taught and the blind don't know Braille. They are simply not allowed to study. For the moment, persons with a disability are represented by five members of Parliament; we also have representatives at community level, but no one listens to them, they are not even allowed to open their mouth. When I compare that with the situation here, I see that disabled persons have quite a few facilities at their disposal here. We, and Africa as a whole, are in a bad situation.

Ann: I'm 100% conscious of that. I have rheumatism and have been in a wheelchair for a while, but I cannot move myself with my arms, so I was continuously dependent on others to push me. When I received an electric wheelchair I was able to go anywhere on my own, I could practice sports. I'm well aware of the luxury I'm living in, but I'm quite happy to have that luxury in Belgium.

Robin (MPI student): An electric wheelchair is very important to be independent. When my electric wheelchair broke down, I constantly had to ask other people to do everything for me. Without my electric wheelchair I feel even more disabled.

Marian: I'm the mother of an eight years old son who recently also got an electric wheelchair and this gives him many new possibilities. I'm not so familiar yet with young persons with a disability, but when I hear them talking, it doesn't seem so easy to continue to study and to find work. To be able to function fully as a human being in a working environment won't be easy. The (economical) opportunities in our society render it also possible to put highly technological means at the disposal of people with limitations. But I think it must be difficult for people with disabilities just because of this highly technological and economically strong society. When applying for a job and in the work situation, it always has to be perfect. It's especially people who are good looking, who function perfectly well, which can work as fast as possible who get all the opportunities. And anyone who, for any reason, does not satisfy to these demands, not even for reasons of a recognized impairment, will usually drop out everywhere. That's the disadvantage of this demanding society. Many opportunities on the one hand, but high demands to everybody on the other hand. I wonder if this kind of pressure is less in the South.

Our society is very demanding, what about yours?

Nimal/Sunethra: The social pressure on persons with a disability to do what everybody else does is growing. There's a pressure to be the same: to do sports, to marry and to have children. It's very difficult to satisfy these demands but the pressure exists. Ten years ago it was not like this.

Idriisa: The biggest problem is the lack of aids for mobility, because they are very expensive. There's only one shop and we don't make them ourselves. It is very difficult for disabled people to move over long distances. But there's no pressure on the disabled to be equal.

Herman: I find plenty of shortfalls in our school system. The society has a problem with us, disabled persons, they're unable to give an answer to people who are a bit different. I find that, in a society of which people with a disability are full members, it is evidently that the school has to find an answer. Plenty of problems are probably connected with this, but I find that our system must be flexible enough to make it possible to complete our education in our own environment. That's the society's task. OK, we have also to stand up for ourselves, but we need plenty of concessions from the society to take us up.

Katty: The GON project, i.e. normal education for young persons with a disability, exists only since the sixties or seventies. Mind you, that's what I've done myself. I think it's not so simple to change the mentality of a society completely in a thirty years towards complete tolerance. I fully agree with you, and I don't minimize our problems. I just find that all this has begun just over 30 years ago. We have to stay realistic. We have to stand up for ourselves and the society has to change, but I still think that it can only grow slowly.

2. The two other themes have appeared already. In Uganda, employment is the biggest wish that is aimed at. A while ago one said that, in Sri Lanka for almost ten years, there's the pressure to marry and to have children. How important is that?

Nimal: Once you're independent, it is normal to marry and to have children. But Sri Lanka is overpopulated and we have family planning. For reasons of poverty, everybody, except the Muslims and the Tamils, will stop procreating after having 2 or 3 children. So, there's an opposition against disabled persons. Only a few of them do have children.

Idriisa: It is our right, even when we are disabled, to have children. For a man it is not so difficult to marry a woman, the only condition is to have a steady income, and one does not look at your disability. But most of them cannot meet a woman to marry her, while they're living on the streets.

The other participants agreed on the fact that everybody has the right to have children, that children are an important part of life and that children find disabled parents quite normal as long as they are familiar with them from an early age. Still, one has to look at hereditary disabilities. How children can be decently cared for and educated is still a question indeed. To find a partner and to earn an income were also mentioned as factors that were considered as being important.

3. What about income, it has been repeatedly mentioned in relation with being independent and having children, how important is it to earn one's own living?

Idriisa: I've talked already about the negative attitude of valid persons: they do not want to recruit persons with a disability. It would be a bit easier for disabled persons if they had an income: they'd be respected in the society, they could study, to marry would be normal, especially for men. When you have an income, one does not look at your disability. The government and the donors should build strategies to make

persons with disabilities stronger, they should support income-generating projects. Persons with a disability are the poorest of the poor all over the world, and certainly in Africa. We receive no money because we cannot offer certainties, but maintaining institutions will become dearer every year. The solution is not to abolish the financing but to reorient the funding. They can support disabled persons in their integration in society by certain projects. We have to address the donors for money while the banks don't want to lend us money. Some people with disabilities would like to start their own small business but they have no starting capital. That's the reason why most disabled persons have to beg.

Nimal: If I had money, I could help other persons with a disability. In the countryside there are plenty of people in need. I could help them with my organisation. But it is not easy to get a job. There are so many unemployed people already. They often try to get a job abroad. By introducing the new regulations, the government decided to give a number of jobs to persons with a disability. But the problem is training and transport. Disabled persons are less educated. What job can they do then? Sometimes you can see disabled persons working as lift boy or employee at the post office. But that's the kind of small jobs for which they qualify.

Ani from Romania (who arrived in the meanwhile): Considering the actual economical and financial situation in Romania, it is difficult for disabled persons to acquire an income. The law does not represent our interests. We get a small allowance but have to give it up if we get a job. I don't understand that. We are people with a disability, we want to be useful to the society, but our handicap remains. The government has many prejudices against us. They think persons with a disability can't do anything, that they cannot be useful to the society. My organisation wants to change that mentality. It's an organisation for valid as well as disabled persons, so as to let integration happen as efficiently as possible. In the IKON Foundation, disabled persons are treated equally, they participate to different social activities to prove that they can do quite a lot. A few examples: the 5th of May last year, we organised protest against the department treating the issues for disabled persons, accommodated on the 3th floor. How can this department serve us if we can't even reach it? This problem has been solved. We also had a campaign to explain to the population that about 20 children with AIDS were living cut off from the outside world without any support.

One does not make life easy for persons with a disability if they have a job already. In Belgium there are social benefits indeed, but I've heard already that to earn one's own income is in fact much preferable.

Katty: Yes indeed. I prefer an income to a subsidy. These social benefits are partly a replacement income if you're not working, then it's normal, if you work, to lose this part of the replacement income. A part of this benefit is meant for social integration and, depending on the level of your income, you can also lose a part of it. I can give you the example of a cohabiting couple that cannot marry because they would then have less income. They've also stopped working because they were keeping less than with a replacement income; they were working in a sheltered workshop where you're paid less. In fact, this is a pity because it does not stimulate persons with a disability to go and look for work. You thus stimulate dependence of course.

Anja (PHOS employee): I find it very important to have my own income, not only for the income as such, but also for the contacts that the job brings with it, and you also have the feeling to make yourself useful in the society. My income makes a big difference with the allowance, but it becomes quite a dilemma if you earn only as much if you work than if you did not go to work. If I worked half-time, I'd have almost as much as I have now. I nonetheless prefer to work full-time because I find that I'd have to stay a bit too much at home if I worked only half-time.

Benoit (student higher education): To find a job is very important because this determines your independence. It is freedom. With the money from the state, you cannot do what you'd like to do. First because it's limited, and secondly, if it would be more, you'd get hints from society. That's why it is nice to own your own money and to decide by yourself how you will use it.

An: Self-respect and independence, to contribute a bit to society, are important but I'm a bit frightened by it. Now it is already difficult for people without a disability, thus for the disabled... but I'm going to try anyway!

Ani: Social contacts are important. I'll give you my own example. There's a big difference since I've been working. My neighbours have more respect for me now. They even ask my advice or they want me to help them with some documents. Their attitude has changed since I've got a job.

At the end of the debate we can say that the following matters attracted the attention:

- **All over the world big efforts are made to interpret human rights in general into rights for children and young persons, including young people with disabilities. But it is not so easy.**

When comparing with countries as Uganda and Sri Lanka (who also differ between them), we realise that the financial and economical factors play quite an important role, so it seems that we only talk about luxury problems.

- **But there are also similarities: we have the right to earn an income, the right to live as normally as possible, the right to marry and to have children etc. But the mentality in the society certainly does not stimulate this, even if it is for different reasons in each continent.**

- **A striking difference - that could possibly have something to do with these reasons - is that the foreign hosts lead a rather personal fight, or through organisations, to obtain certain things, whereas from the public here we hear things like: there should be a service that helps us with, the society should provide us with this or that,... Is that so, or don't all of us have to fight in a modified situation?**

Workshop : behind the photograph.

INTRODUCTION

Description and objective of the game.

It is the objective to construct a realistic story in view of photographs of people with or without a disability, from North and South. It is a playful way to make assumptions explicit. After this exercise, the real story of the people on the photographs will be told, compared with the invented story and the assumptions discussed.

Participants.

The guests from Romania and Uganda.

The speaker from the U.K.

1 Student higher education.

Staff member Light in the Darkness

Board member PHOS

4 pupils school

Teacher school

COURSE

Three photographs were presented, one from India, one from Uruguay and one from Angola. All were people with a disability. The invented stories were written on the blackboard. When there were opposite opinions, both opinions were written down.

Afterwards, the real stories were told and also written down to make comparison more easy to do.

DISCUSSION

During the comparison between the invented stories and the real ones, assumptions present in everybody's head were searched for :

- The colour of the skin is important : the more dark the skin, the more we think they live in difficult situations.
- In developing countries, people live always in more difficult circumstances than people in the West/North.
- We assume that sustainable relations and children are not part of the reality of people with a disability.
- We do not expect people with a disability to have social standing.

Why is it this way ?

- Dished up by the media as such.
- We depart from an ideal picture where being different, being disabled doesn't fit.
- We don't know the South well enough, and for sure not the people with disabilities who live there. We do not search for in depth information.

How can we change this situation ?

The next question was asked : do people with disabilities have to extort change or is the society that has to present the changes. The answer was: it has to come from both sides, but people with disabilities surely have to fight for their rights and for changes in attitudes.

Getting to know the foreign guests better.

N. Nimal Jayawardena.

He is coming from Sri Lanka, the beautiful country that has for long been known as “The Pearl of the Indian Ocean”. It was a country where many ethnic groups lived together in peace and where physically disabled people were rare. Today, this situation is completely different.

Nimal is 44, the eldest son of a family with one more sister and two brothers. When he was young, he developed bone tenderness (Osteoporosis). He never went to school, but today he is a student of the Open University of Sri Lanka. As a child, he was only able to read a few pages because schools for physically disabled people were rare. In the meanwhile, this situation has changed and almost every district has homes for physically disabled. The fact that he started reading and writing little by little gave him the courage to fight for his dreams: to serve society.

At the age of 32, he met Ms. Sunethra, the mother of Suhada Home, a house for disabled children. She took him in and made him participating in several training sessions. This way, he learnt gardening and held floral exhibitions. He had also a training on working with mentally disabled people.

He also participated in a 3-days media workshop. There, he was appointed as a staff correspondent for the magazine “Gemma”. He learnt to design lay-outs by computer and became member of the sales and publicity committee. Then, he took a course of study in mass media, became adviser of “Siyasa, an Independent Journalists’ Group” and by now he is assisting the second year of sociology at the Open University of Sri Lanka. He is working voluntary in several organisations: organisations of journalists and in service organisations.

Working in these organisations and assisting a course in social service made it possible to found an organisation: the Shanthi Seva Community Development Foundation, of which he is the chairman. The objective is to improve the education of the children in the border village Dambepitiya.

On this moment, the powerful countries are involved in a big fight in which a lot of people become physically disabled. Many third world countries suffer a lot due to terrorism. This is also the case in Sri Lanka. There are many organisations that want to do something about, but they need support and money. In Sri Lanka exists a big need for equipment for disabled people and he invites producers to meet these demands. He asks also if it would be possible to get some space on the western market for their products because this would help them a lot.

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IDRIISA KIRAGGA.

He is the chairman of the Foundation of Disabled Muslim Youth Association in Uganda, an organisation founded in 1995 with the aim to promote the integration of people with a disability into the society. The organisation counts 156 members.

The Foundation organises sports activities like football, netball, djembe and dance, for children as well as for adults. For some happenings they invite also able-bodied people, but they do not come because of a negative attitude they have in relation to disabled people. They try to do something about it by organising seminars, but it is also difficult to get attention on this. Despite these efforts, they keep on organising sports activities to keep body and mind in a good shape and to show that people with a disability are also able to do something.

In the actual government of Museveni, women, youngsters and people with a disability are represented in the Parliament and in all district councils, but this doesn't mean that the attitudes in relation to people with a disability already changed. These representatives are not heard even.

The live for disabled in Uganda stays very difficult: education is not accessible, lack of aids, roads and buildings are not accessible, no possibilities for employment, a negative attitude in general,...This way it is difficult to take part in the live of the society, don't even think about decision making. To change something, people with a disability should earn an own income. Therefore, the organisation tries to get projects on income generating, principally by manufacturing of objects of general use. For these projects, they try to find financial support with foreign donors. 'Aid to Artisan', an American organisation gave them some support already.

They try to find also permanent sources of income for the organisation. They want to buy a certain amount of cows, which produce daily a lot of milk and by selling this milk, they could get permanent income. A Finish organisation called 'Abilis Foundation' seems to be interested to finance this project.

The Youth Association is member of an umbrella organisation: the National Association of People With a Disability of Uganda. This association counts 56 members and tries to defend the interests of the members. They have also contacts with international organisations like Mobility International, which on their turn bring them in contact with other organisations like PHOS, and which invite them to certain seminars and workshops.

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ANI ZAHARIA.

She is the public relation responsible at the IKON Foundation in Galatz, Romania. The IKON Foundation is a non-governmental organisation, since 1995 offering social, humanitarian and educational support for all the categories of deprived persons.

The main objectives are:

- changing the human mentality;
- involving the citizens in taking decisions on the level of the community;
- improving the communication skills of these persons;
- defending the environment rights;
- helping to integrate into the society the different categories of disadvantages persons, no matter the origins of the disadvantage.

The activities are structured in 4 different departments:

- civic
- health
- environment
- communication

The IKON Foundation involves children and young persons in interactive programmes for the development of their personality and the capacity of individual evolution and group evolution.

All activities have as goals:

- immediate improvement of life;
- increase of individual skills;
- organisational development on the long term.

Projects finalised:

- Leader course for disabled persons – forming leaders in communication – 1999
- Integration from identity – symposium for disabled persons – 1999
- Exhibition with paintings of deaf children – 1998, 1999
- Acquiring knowledge, playing and travelling in the summer holiday, for 20 children with AIDS – 1998
- Together and solidary – project in partnership with France – for the same children with AIDS – 1998
- The tree of citizens' wishes – 1998
- National competition of table tennis for persons with a disability – 1998
- Non-smoke campaign – 1997
- Specialising course for writing application forms for financing, with trainers from the National Democratic Institute – Washington – 1997
- The tolerance at the national level – 1997

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