

Young Voices on the UN Convention on the Rights of Persons with Disabilities

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Executive Summary

This report summarises the findings from a series of focussed discussion groups carried out in late 2005 and early 2006. The groups brought together 222 disabled people from 12 countries. They were nearly all aged between 17 and 26, roughly equal numbers of young men and women, and with a range of disabilities.

Why go to such lengths to consult with young disabled people?

Firstly, because although in many developing countries young people make up over half the population, they are rarely consulted.

Secondly, because as the United Nations moves towards a “Comprehensive and Integral International Convention on Protection and Promotion of the Rights of Persons with Disabilities” (UN Convention), it seemed essential to allow an opportunity for young people to validate, add to, or disagree with the issues that are forming the articles of that Convention.

And thirdly, because the world in which disabled people live desperately needs greater engagement with new young leaders and thinkers. The process of consultation could perhaps play a role in developing new leadership for the future of the Disability Movement.

Young people met over three days for discussions, carefully facilitated to allow maximum opportunity for their own ideas to emerge and be recorded. There was broad agreement on the five

issues that most affect these young disabled people: access to education; lack of employment; discrimination and lack of awareness by non-disabled people and negative attitudes; poor compliance with existing legislation; and lack of access to health provision.

As well as these, a further 20 issues are discussed in the report, some of which were of particular concern to certain groups. While the majority of areas discussed and personal testimonies provided serve to validate the issues already raised in the Convention development process, the emphasis given to certain issues by young people is of great interest. In particular the clear threat, and frequent incidence, of sexual harassment and abuse is of major concern.

Overall, this ambitious project has been an outstanding success in terms of the process of involving young people. This will be continued with their representation at the next Convention meeting in New York, and by follow-up discussions and eventual monitoring of the Convention. The extent to which young people felt able to share often deeply personal issues is a tribute to the facilitation of the work, but more importantly to their own energy and desire to play a central role in the decisions which will affect their lives in future.

Introduction

All too often the voices of young people are not heard in the process of designing legislation that will affect their lives. In many developing countries, people under the age of 25 make up over half the population. Indeed, according to UN estimates at least 45 per cent of the population in most African countries is under the age of 15. With legislation that affects disabled people, not only are young people excluded, but also until recently “professionals”, who were able-bodied people who came from a medical or charitable background, made decisions. With the emergence of country and international movements of disabled people, this has changed to a large extent, but young people are rarely asked their views.

‘Voices of Young Disabled People’ aimed to change that by systematically consulting young disabled people in a wide range of countries. The idea originated following discussions with groups of young disabled people, NGOs and development agencies in West Africa that highlighted the fact that young disabled people were a neglected group whose voices were never heard. It was then discussed within Leonard Cheshire International (LCI) as to how this could be taken forward. Involvement in UN Ad Hoc Committee meetings gave an opportunity to rethink the idea and develop a concept that would enable the building up of new leadership and to help create and consolidate existing grassroots level movements. LCI has active



Jenny Matthews/Leonard Cheshire

partnerships in 54 countries, which provided a good opportunity to pilot focus group discussions (FGD) with small groups of young disabled people.

It was vitally important that the views of young disabled people were sought within a framework; all too often marginalised people are “consulted” and their inputs used for research, and not for the benefit of those whose views are sought. LCI is, therefore, committed to enabling young disabled people to participate in the process of building the Convention. This offers an unique opportunity to involve them in a global process that should help in developing their understanding of human rights and active citizenship, while providing a platform from which to directly articulate their views. What could be more empowering than that?

A United Nations Convention is an international agreement among states to be bound by the provisions of that Convention. Previously agreed United Nations Conventions include, among many others, the International Convention on Cultural and Political Rights, the International Convention on the Rights of the Child and the International Convention on the Elimination of All Forms of Discrimination

against Women, while others outlaw torture, inhuman and degrading treatment and slavery. The purpose of the proposed “International Convention on the Rights of Persons with Disabilities” is to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities, and to promote respect for their inherent dignity” (Article 1 – Purpose).

The process towards the proposed Convention began in 2001 and was followed by a series of Ad Hoc Committee meetings that have been held in New York. Negotiations on the Convention are expected to be completed in 2007, followed by a period of ratification by the required number of states before it comes into force. The Convention aims to set global standards for states to address the needs of disabled people across the world in the areas of education, health, women with disabilities, children with disabilities, awareness raising, accessibility, right to life, freedom from exploitation, violence and abuse, work and employment, participation in political and public life, among other areas which are important in the lives of disabled people.

There is also a “side agenda”. From the beginning, this project has recognised that the process of genuine involvement of young disabled people could have an important value. The Disabled Peoples’ Movement emerged in the early 1980s, influenced as it was by the formation of

Disabled Peoples’ International (DPI) in 1980, the declaration by the United Nations of 1981 as the International Year of Disabled Persons, followed by the focus provided by the Decade of the United Nations World Programme of Action Concerning Disabled Persons (1983-1992). Since that time disabled peoples’ organisations (DPOs) have emerged throughout the world and many have played important roles in developing and lobbying for legislation that has very significantly improved disabled people’s lives. But the movement needs new leadership and the drive and energy that young people bring. It is anticipated that many of the young people who have taken part in the process so far, will become involved in monitoring the International Convention as it comes into force. LCI will continue to work with DPOs to facilitate this process. This first hand involvement of young disabled people with their fundamental rights is aimed at ensuring the Disabled Peoples’ Movement is empowered with a new source of activists.

Methodology

Leonard Cheshire International is ideally placed to make contact with young disabled people in selected countries of the regions in which the organisation is active (Asia, Africa and Latin America). This gave LCI the ability to get in touch with young disabled people with a range of disabilities. Their network of partners include Leonard Cheshire Services and also, increasingly,

DPOs. Recent strategy to make a conscious effort to work with DPOs to build genuine partnerships is being taken forward at all levels of policy and programme implementation

Fifteen countries were chosen and, of these, twelve carried out consultative workshops (referred to as focus group discussions (FGD) in this report).

“...extend our deepest thanks for giving us the opportunity to let our voices be heard, which is a rare opportunity.”
(*Sierra Leone*)

These were in Asia: Philippines, India and Sri Lanka; Africa: Uganda, Kenya, South Africa, Sierra Leone, Namibia, Botswana and Swaziland; and Latin America: Nicaragua and Honduras. Guidelines on how the workshops were to be conducted were drawn

up (available from LCI). They asked that participants should be between the ages of 16 and 25 (preferably above 18). They provided for a process over three days that was highly participative with an emphasis on ensuring that the young people’s views were expressed with as little guidance or “steering” as possible. Workshop facilitators were also offered telephone support from the co-ordinators to ensure that the process was as similar in each country as possible, and that they were confident in the objectives and intentions of the process.

The process asked the young people to brainstorm all the issues that most affected their

lives, and then to focus in on those which were most important, eventually arriving at the five areas which were most significant. They then went on to discuss what changes they would like to see in these areas, and who might enable these changes to take place.

Participants

222 young people took part in the focus group discussions. With few exceptions they were between the ages of 17 and 26 and included young people with the following disabilities:

- 50% had mobility related disabilities
- 18% were visually disabled
- 14% had hearing disabilities
- 7% had intellectual disabilities
- 5% had multiple disabilities
- 2% were people with mental illness
- 5% had either epilepsy or albinism.

We believe this represents a reasonable cross section not unrepresentative of disabled people, with the exception of mentally ill people who were not well represented. (In any follow up work efforts should be made to address this). With more time and resources more young disabled people in more countries could have been consulted, but we believe that the sample chosen represented a very significant cross section of countries and disabilities.

Inevitably, with limited resources, there was an urban bias and it would be important to try and address this in future discussion groups: the



primary concerns of some groups around issues such as transport and education may well be very different in rural areas. In some countries there is a gender bias – but overall the split of 53% male to 47% female was very satisfactory. In some countries a particular group of young people with one disability weighted their concerns in a given direction (for example the mobility issues of the largely physically disabled group in South Africa). However, the total sample gives a wide representation and thus the overall range of issues of different groups have most probably been aired.

In two countries the age range was increased because of perceived difficulties in finding enough young people. We feel that in these cases conversations may have tended towards issues that affect all disabled people (rather than those which specifically affect young people). However, there is no evidence that the few older people have influenced the overall picture very significantly, and the average age of 23 is exactly what the project was seeking. Full details of the composition of the groups is provided in Appendix 2.

Workshop implementation

In most cases the workshops were conducted following the guidelines very closely. One workshop (Philippines) had to be held before the guidelines were completed, but the essential elements of their work retained a significant value. In some cases initial time was spent explaining the UN Convention,

but extensive time was still allowed for participants to have free and open discussions about issues they originated themselves. A few others made minor changes to wording of questions to reflect the needs of translation or local situations. Again, we believe these did not significantly alter the nature of the intended work that took place.

Process

Without exception there was pleasure and gratitude from young people in relation to their involvement in the project:

“We would like to extend sincere gratitude...for giving us this opportunity and holding such an event that made us feel “nothing about us without us.” (Sri Lanka)

“I thank you for meeting all of us and for the opportunity to share, especially about the issue of human rights.” (Honduras)

“...extend our deepest thanks for giving us the opportunity to let our voices be heard, which is a rare opportunity.” (Sierra Leone)

There was also recognition of the value of continued engagement:

"Their request was that the discussions should not end here and just be a talk show." (Namibia)

"The youth asked that there be more meetings of this nature." (Nicaragua)

"It was their first time to be with a group of (other) disabled people and discuss issues affecting them. They requested that there be more opportunities availed for such forums." (Swaziland)

The key issues

An analysis of the issues focussed upon by each group has been made. Appendix 1 provides a table that sets out the main areas raised by the young disabled people. For two reasons the list should not be treated as showing a strict order of priority.

Firstly, differences in languages and cultural focus

mean that it has sometimes been difficult to tease issues apart.

Secondly, many issues are closely connected to others and were discussed under both headings by different groups. For example negative attitudes were

discussed along with education, access to transport, and health provision, as well as a discrete subject. However, while accepting that straight "scoring" is unhelpful, strong patterns emerged and the issues fall broadly into four groups:

- Those that were a very high priority for at least half of all the groups
- Those that are a very high priority for at least two groups and a high priority for most of the rest
- Issues that were a high priority for a significant number of groups
- Those that were a minority concern, but still represented an important issue for that particular group.

1. Those issues that were a very high priority for at least half of all the groups:

- Access to education
- Lack of employment
- Discrimination, lack of awareness by non disabled people and negative attitudes
- Poor compliance with existing legislation
- Lack of access to health provision.

2. Those issues that were a very high priority for at least two groups and a high priority for most of the rest:

- Strengthening of DPOs at both country and African (continental) levels
- Communication and increased use of Braille and Sign Language

"...sciences are compulsory and yet blind students cannot handle concepts that require vision – chemicals for example..." (Uganda).



- Access to information
- Physical access to private and public buildings
- Personal relationships
- Vulnerability to sexual harassment and other issues relating to marriage and women's rights.

The Draft International Convention on the Rights of Persons with Disabilities already covers most of these issues, and they therefore validate the core articles from the point of view of young people. In some cases there is a particular experience that young people bring (for example, corruption and poor political leadership; strengthening DPOs at both country and Africa levels; and disabled prisoners' rights), and in others, their views are new ("identification of the hard of hearing and deaf"). Below, each of the areas listed above is illustrated with personal experience, linked to the relevant article in the draft Convention, and annotated with a brief analysis from the report's authors.

■ Access to education [Article 24 of Draft Convention (DC) – Education]

Perhaps not surprisingly in discussions between young people, the right to education is amongst the

top three issues for 75 per cent of groups.

Discussion on "access to education" overlapped with "communication" and "negative attitudes" considerably. How could sound education take place without communication and without disabled youngsters being treated equally?

"...a young deaf woman narrated her struggle as a student..... Sometimes the teacher would send her home because she regarded teaching her as an additional burden and a waste of time..... in public places her classmates are unkind to her...and even make fun of her when she makes sign language." (Philippines)

"At school it was like they enjoyed making me miserable and uncomfortable." (Sri Lanka)

"...sciences are compulsory and yet blind students cannot handle concepts that require vision – chemicals for example..." (Uganda).

"...she could not take part in activities (because of physical disability) leading to frequent punishment by teachers irrespective of her disability." (Kenya)

"I didn't go to school, people laughed and that affected me because I didn't learn." (Honduras)

But there are heartening tales of progress:

"Another said that she felt frustrated.... Because she could not finish her exam on time as she had difficulty

writing. Her teacher reprimanded her and discouraged her from continuing her studies. This inflamed her determination. She told the teacher that knowledge should be measured by ability not inability to use hands for writing and she challenged the teacher to give her an oral exam. She perfected the oral exam and from then on the teacher respected her and made her a model student.” (Philippines)

The importance of education cannot be overemphasised, as without effective access to it, disabled people are unlikely to have the tools to compete on an equal basis with others.

■ **Lack of employment [Article 27 – Work and employment]**

Here too, a number of issues sit under one heading. Lack of education and discrimination feature heavily in discussions on how hard it is to obtain employment by disabled people:

“ ...she submitted her resume...and was informed of an interview. She was in high spirits to attend the interview. However, the personnel on seeing her as a person with a disability cancelled the interview although her transcript of records was impressive. She was dismayed and angry..... the personnel replied they could do nothing about it.” (Philippines)

“There is no match between one’s education and employment.” (India)



Leonard Cheshire

“Everywhere I go they ask for experience, but without the chance to work, how can I have experience?” (India)

“Youth with disabilities are used as cheap labour... overtaxed and financially exploited... last to be considered for employment and the first to be sacked...” (Uganda)

Where the reports comment on it, most of the young people in the groups were unemployed. The extent of barriers to employment is massive, especially in countries where unemployment rates are exceedingly high amongst the general population. Furthermore, employment opportunities are closely linked to educational levels attained¹.

Even if a young disabled person does manage to get a job, lower salaries and benefits may be imposed: *“..... Companies accept them (disabled people) for a job on condition that they would be given lower salaries and would not receive any benefits. Because of poverty many were forced to give in to these conditions.” (Philippines)*

¹ Living Conditions among People with Disabilities in Namibia, 2003 , 'A National, Representative Study', Published by the University of Namibia and SINTEF

■ **Discrimination, lack of awareness by non disabled people and negative attitudes [Article 5 – Equality and non-discrimination; Article 8 – Awareness raising; Article 12 – Equal recognition before the law]**

This subject weaves throughout most of the conversations, illustrating how much the lives of disabled people are dominated by discrimination and harmful attitudes and this was the number one concern in five of the groups. Stigma and discrimination often play a part in why a given right is not available, but there are also innumerable examples of “straight discrimination”:

“My parents did not allow me to use a mobility cane as they thought it would give strangers the right to hold my hand.” (India)

“...the court refused to consider me as a witness as I am visually impaired.” (India)

“Why does the general public put disabled people in the category of beggars, poor and destitute?” (Sri Lanka)

■ **Poor compliance with existing legislation [Article 33 – National implementation and monitoring]**

This was a major area of discussion, both around disability specific legislation that is not implemented – such as quotas for employment – and where disabled people are discriminated against. The group in Uganda – which has some of

the most extensive rights for disabled people that exist – placed lack of enforcement as their highest priority. This has particular resonance for this project in which new legislation is the key aim.

A recent study focusing on implementation of disability policies and law in South Africa confirms the wide gap between policy infrastructure and its implementation².

“I was a driver before becoming disabled.... although disabled friendly vehicles are available, persons with a disability are not issued a licence.” (Sri Lanka)

“Many [disabled people] lose their right to inheritance of land, livestock etc. Relatives use the pretext of care-taking to disenfranchise the person with a disability”. (Uganda)

“Some parents do not register the birth of a disabled child, hence many lose their identity and the right to own property.” (Uganda)

■ **A lack of access to health provisions [Article 20 – Personal mobility; Article 25 – Health]**

Issues of health were not a first or second priority for any group, but seven groups had detailed discussions and it comes up as an issue in other areas. The costs of medical equipment came up a

“...the court refused to consider me as a witness as I am visually impaired.” (India)

² ‘Disability policy and legislation’ A K Dube 2005 www.disabilitykar.net/research/small_sa.html

number of times and, in particular, the injustice of excessive import duties, and VAT. The negative attitudes of health professionals were cited as one of the problems contributing to poor access (for example, the view that disabled people are asexual and, therefore, why they should seek reproductive and sexual health services).

“There are no proper clinics for therapy, assessment or counselling ...” (Sri Lanka)

“Health practitioners are usually unkind to young disabled people...” (Uganda)

■ **Strengthening of DPOs at both country and Africa levels**

Four groups discussed the need for stronger disabled peoples’ organisations (in Botswana, Namibia and Sri Lanka it was amongst their top priority areas). These discussions linked the need for stronger movements to other issues, such as the

need for improved legislation and for existing law to be better implemented. They also felt that improved representation would increase disabled peoples’ profile and assist in breaking down barriers and changing attitudes.

“Some religions do not welcome discussing issues of disability... disability is often associated with sin and demons.” (Kenya)

■ **Communication and increased use of Braille and Sign Language [Article 2 – Definitions; Article 9 – Accessibility; Article 21 – Freedom of expression and opinion, and access to information]**

Group members with visual or hearing disabilities, not surprisingly, placed communication high on their agenda. (The fact that – despite strenuous efforts to fund and facilitate the full participation from these participants, there were some instances where this had not been ideal, illustrating how far there is to go even in “ideal” circumstances.)

“Lack of understanding of communication used by young disabled people leads to poor relationships with society and thus breakdown in social relationships.” (Uganda)

Where Sign Language is used, there clearly remains an issue about the extent to which it is sufficiently developed to allow full communication, and:

“I don’t know even sign language, the people who know want to show me, but sometimes I don’t understand.” (Nicaragua)

■ **Access to information [Article 2 – Definitions; Article 21 – Freedom of expression and opinion, and access to information]**

As well as the specific issues of communication in the area above, five groups took time to discuss in detail the issues of how they are systematically



excluded from information sharing. In most cases this centred on lack of access to new information technology (IT) opportunities and was linked to education and to employment opportunities. Without information on what was available, how could they receive training and have a chance to get ahead?

Physical access to private and public buildings [Article 9 – Accessibility]

Physical access is often linked to discrimination and/or lack of understanding by the public, and this can greatly exacerbate the disadvantages faced by disabled people:

“The computer training centre is on the first floor where a person like me with physical disability finds it difficult to reach.” (India)

Personal relationships [Article 23 – Respect for home and the family]

Although only a specific area of discussion in four countries, personal relationships were touched upon in different discussion areas in most countries, and in Honduras it was their major concern. Sometimes the issue was simply that for disabled young people it is just not a topic to be discussed:

“Why can’t we talk about marriage?” (Sri Lanka).

“We have a right to fall in love.” (Nicaragua)

“...they [health practitioners] do not expect young disabled people to have relationships . There is an assumption that we are not sexually active.” (Kenya)

And as a further example of ways in which the structures of society make things worse:

“Some religions do not welcome discussing issues of disability.... disability is often associated with sin and demons.” (Kenya)

Vulnerability to sexual harassment and other issues relating to marriage and women’s rights [Article 14 – Liberty and security of the person; Article 15 – Freedom from torture or cruel, inhuman or degrading treatment or punishment; Article 16 – Freedom from exploitation, violence or abuse; Article 17 – Protecting the integrity of the person; Article 22 – Respect for privacy]

This issue came up significantly, both in an underlying way and in particular incidents of major abuse. It is obviously an area of major concern for young disabled people.

“Youth with disabilities are always sexually exploited before they can be offered employment possibilities.” (Uganda)

“One female participant reported that she had been raped. The rapist took advantage of her short physical stature to transport her in a basket to his residence. She had no courage to report the fact that she had conceived from this rape although she later had a miscarriage.” (Country withheld)

“Sexual exploitation of disabled women and girls is so pervasive in Sierra Leone that immediate action should be taken to minimise and/or eliminate it.”

“A case was made where a blind person was required by law to identify somebody who had raped her.” (Swaziland)

In India and Kenya the particular vulnerabilities of women with intellectual disabilities was highlighted. (The lack of participants with mental illness highlights how much this remains a hidden and marginalised issue.)

Although not specifically highlighting sexual vulnerability, the South African group noted “persons with disabilities are targeted and are easy prey for criminals”.

3. Issues that were a high priority for a significant number of groups

- **Lack of relevant legislation**
- **Corruption and poor political leadership**
- **Political representation and participation**
- **Poor access to services**
- **Access to transport**
- **Lack of information about HIV/AIDS**
- **Identification of the hard of hearing.**

As before, each of the key points above is illustrated with personal experience and linked to the article in the draft Convention and comment from the report’s authors.

■ Lack of relevant legislation and policy [Article 3 – General Principles; Article 4 – General obligations]

The absence of policies and/or legislation addressing the specific needs of disabled people is a major problem in two countries in which this consultation took place (Botswana and Swaziland). Disabled youth showed an acute awareness of the implication of a policy vacuum on their general welfare.

■ Corruption and poor political leadership

Although not registered as a “top five issue” except in Namibia, corruption that drains resources targeted to disabled people was cited as a concern in the Philippines, Uganda and Kenya. It was recognised that for young people there is no benefit from corruption now (nobody bribes young

people!) and only a later cost in lost benefits.

Corruption at government level was also reported, "...some institutions use the name of people with disabilities, but then use the funds for their own benefit..." (Namibia). There has been a high profile campaign in Namibia against corruption in high places led by the State President, which may partly explain the priority accorded to the issue by youth in the country.

■ **Political representation and participation [Article 29 – Participation in political and public life]**

As well as calls for increased opportunity to take part in democratic processes, there is the issue of enabling people to vote more easily: "... disabled persons should get the opportunity to vote the way that confidentiality is not broken" (Sri Lanka). For example, in a growing number of African countries (Uganda, Namibia, South Africa among others), disabled politicians are emerging as representatives of the disability movement at different levels, including parliament. The increasing visibility of the disability movement and its lobbying is creating these new opportunities for engagement with governance processes. The very nature of representative democracy is thus being challenged to reform in order to incorporate marginalised voices in society.

■ **Poor access to services [Article 4 – General obligations; Article 24 – Education; Article 25 – Health]**

Where services are available, cost is likely to be an issue: *"Due to colostomy operation....my biggest worry is access to medical equipments I need for daily usage. Their costs are unbearable.."* (Sri Lanka)

This issue intersects strongly with education, health and discrimination.

■ **Access to transport [Article 9 – Accessibility]**

Again, this is sometimes an issue of discrimination, and sometimes of physical access. It is, nevertheless, a prevalent problem in many developing countries. Either way it leads to:

"...when bus drivers see us at a bus stop, they don't stop." (Sri Lanka)

"Even when a bus stops it does not wait for us to get out." (India)

■ **Lack of information about HIV/AIDS [Article 9 – Accessibility]**

Although issues around HIV/AIDS were only formally a key concern in Swaziland, it is also touched upon in other countries under both communication and health. Lack of communication and education for people with hearing and visual

"...when bus drivers see us at a bus stop, they don't stop." (Sri Lanka)

impairment is noted as a huge challenge:
“Youth with disabilities are sexually vulnerable as they consider getting a partner as a privilege and are more willing to expose themselves to disease and HIV.” (Kenya)

“There is currently less information communicated to disabled people on HIV/AIDS...especially the blind and deaf because all the information is in print and not translated.” (Swaziland)

“AIDS Voluntary Counselling and Testing centres are not equipped to handle youth with disabilities.” (Kenya)

■ **Identification of the hard of hearing**

This was a key issue in Sierra Leone that “sparked off heated debate”. People with hearing impairments frequently need some way in which they can be recognised and shown understanding. The comment is included in the report primarily because it demonstrates the need for debate at different levels in different countries – and in Sierra

Leone – as it emerges from years of civil war – the young people had some fascinating discussions that illustrate the chronic lack of both awareness and legislation.

“They reject us” ...
 “they tease us” ...
 “there is no respect.”
 (Nicaragua)

4. Those that were a minority concern, but still represent an important issue for that particular group.

In some cases, while an issue only emerged once or twice, it is of particular concern to people with one kind of impairment. It is important not to lose these as although they may be a minority concern, they affect huge numbers of young disabled people in particular situations. The issues include:

- **Family awareness and negativity**
- **Social security, or support for severely disabled people**
- **Awareness of young people’s specific needs**
- **Culture and rights**
- **Sport and recreation**
- **Disabled prisoners’ rights**
- **Care and attention in emergency situations.**

As before, each of the key points above is illustrated with personal experience and linked to the article in the draft and a comment from the report’s authors.

■ **Family awareness and negativity [Article 5 – Equality and non-discrimination; Article 8 – Awareness raising; Article 19 – Living independently and being included in the community]**

This is a particular aspect of discrimination and negative attitudes and was a key issue in three countries. It is essentially an aspect of discrimination and negative attitudes that was a central concern for 75 per cent of the groups, but ignorance, lack of understanding and prejudice



from one's own family is obviously even more hurtful and damaging:

"...her parents thought her disability was infections (so she was) isolated and confined to their house... (and did not start school until aged 10)." (Philippines)

"I was kept hidden from society by my parents." (Sri Lanka)

"Youth with disabilities are likely to be underfed by family members on the pretext that they do not contribute productive work." (Uganda)

"They reject us".... "they tease us"... "there is no respect." (Nicaragua)

The testimonies of youth confirmed the widespread discrimination that affects them

inside their households, which included examples where family members had directly discouraged them from associating with other disabled persons.

"My father rejects other deaf young people. He is always mad at them." (Nicaragua)

■ **Social security, or support for severely disabled people [Article 28 – Adequate standard of living and social protection]**

This came up as a key issue in a third of the groups – although not in their prioritised issues. It is particularly interesting in that, while much of the discussion focused on disabled people's rights to independence, there is also a clear recognition by young disabled people that there are situations in which that ideal is hard to attain. In those cases, disabled people have a right to be supported in medical and other ways to live independent lives on an equal basis with others. Among the countries surveyed, we are aware of only South Africa, Namibia and India where means-tested monthly disability grants are paid.

■ **Awareness of young people's specific needs [Article 5 – Equality and non-discrimination; Article 8 – Awareness raising; Article 16 – Freedom from exploitation, violence or abuse; Article 19 – Living independently and being included in the community]**

Awareness of young people's needs came up as a specific issue in Uganda and Nicaragua, where it

was felt that the disability movement and service providers did not understand young people's specific needs, and on this basis they faced violations of their rights. In the disability movement in Southern Africa, disabled youth are increasingly becoming active in forming structures at the national and regional levels to represent their peculiar interests. This is being done in most instances with the active support of existing organisations of disabled people.

■ **Culture and rights [Article 30 – Participation in cultural life, recreation, leisure and sport]**

The groups in Sri Lanka and Botswana both took time to focus on culture and how it impacts on human rights of disabled people – essentially this being an issue of the right of disabled people to play a full role in society on an equal basis with others. This right was, however, being denied by deep-seated cultural beliefs, norms and values which mediate against the

recognition of the human worth of disabled persons.

■ **Sport and recreation [Article 30 – Participation in cultural life, recreation, leisure and sport]**

The Namibian and South African groups both discussed the need for improved access to

sporting facilities for disabled people. It was therefore not surprising that the disabled youth named their rights in relation to participation in sport and leisure activities, which can offer a platform for organising other youth.

■ **Disabled prisoners' rights [Article 16 – Freedom from exploitation, violence or abuse]**

This issue was raised in Namibia in an animated discussion on the lack of rights, stigma and discrimination, and physical barriers likely to be faced by prisoners. Given abuses that take place in prisons across the world, disabled prisoners may be particularly vulnerable in these environments.

■ **Care and attention in emergency situations [Article 11 – Situations of risk; Article 17 – Protecting the integrity of the person]**

This came up in specific relation to the 2004 Tsunami that resulted in over 700 disabled people from the Nicobar and Andaman islands alone losing their lives. It was felt that particular attention should be given to the needs of disabled people in emergency situations, and in disaster preparedness.

Given the increases in disasters caused by climate change, this would seem particularly pertinent. Specific research (DFID funded) was undertaken following the Asian Tsunami on "Disability and Conflict in Emergency Situations: Focus on Tsunami-affected Areas"³.

"...her parents thought her disability was infections (so she was isolated and confined to their house...(and did not start school until aged 10)." (*Philippines*)

³ http://www.disabilitykar.net/research/thematic_conflict.html

Key points raised in discussions on what changes young disabled people would like to see, and who might carry these out

The main purpose of the focus discussion groups was to ascertain what the central issues for young disabled people are and this took up most of the allotted time. However, some interesting and useful pointers for the future also emerged and these are summarised below.

It was felt important to sustain interest in the Draft Convention by implementing follow-up workshops in the fairly near future to look at how its implementation might be monitored. It was also suggested that a “monitoring group” of young disabled people might extend its brief to existing country legislation, as well as the UN Convention.

The following were all listed as having key roles in ensuring that young disabled people’s rights are attained: DPOs; government agencies; the United Nations; family; friends; church; NGOs and the media. The media came up in many groups and it is clearly felt to be an area in which discrimination could be tackled (relatively easily and with low cost).

While most of the areas young disabled people would like to see addressed are not unique to young people (such as improved physical access to public buildings), some were specific:

- That “people with intellectual impairments deserve accurate, age appropriate, sexual health information”.
- There was also recognition that for young people in rural areas, things may be particularly difficult – there are even less likely to be educational, vocational training, or appropriate health facilities available. Young people felt this imbalance should be addressed through government policy to allocate resources to rural areas.
- In parallel with the emphasis given to young people’s risk of increased sexual and physical abuse, they felt that national legislation should be enacted and adhered to in order to protect young people.
- There were strong calls for improved allocation of resources to enable integrated education to function properly, with associated teacher training, curricular development, equipment and physical access.
- Groups containing hearing impaired people emphasised the need for hugely increased resources to train in sign language. In some cases they request that sign language be “on the school curriculum, just like any other subject”.
- That young disabled people should be trained to carry out education work – in areas like HIV/AIDS awareness, and sign language training, was also mentioned.

APPENDIX 1 – Analysis of issues raised

Where no prioritisation is given, an X indicates this. Top issues are shown in **bold**.

	Philippines	India	Sri Lanka
KEY ISSUES WITH A HIGH DEGREE OF CONSENSUS			
Access to education (and the right to education)	3	2	X
Employment	X	3	2
Discrimination - negative attitudes, lack of awareness (amongst the general public)	1	1	1
Poor compliance with existing laws	2		6
Health	X	6	3
Strengthening DPOs at both country Africa levels			4
Communication - increased sign language and Braille usage			
Access to information.		4	X
Physical accessibility to houses, schools etc			X
Personal relationships			X
Vulnerability to sexual harassment, and other issues relating to marriage and women's rights.	X	5	
ISSUES OF HIGH IMPORTANCE TO PARTICULAR GROUPS			
Lack of relevant legislation			
Corruption and poor political leadership	X		
Political representation and participation		X	5
Poor access to services			
Access to transport	X		
Lack of information about HIV/AIDS			
Identification for the hard of hearing			
ISSUES IN THE TOP 10, BUT NOT THE TOP 5			
Family awareness and negativity	X		
Social security/ support for severely disabled people.		X	X
Awareness of young disabled people's needs			
Culture and rights			X
Sport and recreation			
Disabled prisoner's rights.			
Care and attention in emergency situations		X	

Abbreviations

- UN** United Nations
DPO disabled peoples' organisation
NGO non governmental organisation
FGD focus group discussions
RSA Republic of South Africa
UN Draft Convention Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities

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“We would like to extend sincere gratitude...for giving us this opportunity and holding such an event that made us feel “nothing about us without us.” *(Sri Lanka)*



Leonard Cheshire is a leading non-governmental organisation with 60 years of achievement in promoting positive attitudes to disability and empowering disabled people. The International Department of Leonard Cheshire (LCI) works in 55 countries with over 250 partners. LCI works with disabled people's organisations, international organisations, national governments and local communities. It aims to change attitudes to disability and promotes:

- Disabled children's right to a meaningful education
- Livelihoods programmes to enable disabled people to become independent
- Innovative community-based care and support
- Training and research in post-conflict and post-disaster countries.

We believe that an inclusive, barrier-free and rights-based society will enable disabled people to enjoy greater freedom through economic and social participation.

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