UN Convention on the Rights of Persons with Disabilities:
a call for action on poverty, discrimination and lack of access

Report of a Joint Conference organized by
Leonard Cheshire Disability and United Nations Economic Commission for Africa

Conference held at the
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Addis Ababa, Ethiopia
20–22 May 2008

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Conference PowerPoint presentations and other details may be accessed on the conference microsite, which is available via the conference link on www.lcdisability.org/international.

Selected papers by conference speakers have been published in three special issues of academic journals. These may be found at:

description#description


This report is available in alternative formats. Please contact Diana Shaw at international@lcdisability.org for more information.

Opinions expressed in this report are those of the speakers and do not reflect official policy or practice of the United Nations Economic Commission for Africa or Leonard Cheshire Disability.

Cover: Two boys from an inclusive school in the Philippines
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Dear Reader,

2008 will be remembered as one of the most important dates in the history of the human rights and disability movements. Representing years of campaigning and dedication by people around the world, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) came into force on 3 May. Since this was just weeks before the joint UNECA and Leonard Cheshire Disability conference, its 500 delegates from over 50 countries were among the first to celebrate the world’s newest human rights tool.

Coming in the 60th anniversary year of the Universal Declaration of Human Rights, the UNCRPD reinforces the need for equal rights for all the world’s citizens. 2008 is also the 50th anniversary of UNECA, whose mandate is to ensure that internationally agreed agendas are implemented throughout Africa. Leonard Cheshire Disability was also founded 50 years ago, and works in 54 countries to change attitudes to disability and to serve disabled people around the world.

We frame our opening comments on the UNCRPD in terms of rights, because we applaud the rights-based approach of the Convention. It is only by shifting thinking and action on disability from the “beneficiary” or “recipient” approach to one based on human rights and inclusion that all people can climb out of poverty, achieve equal access and eliminate discrimination.

These issues formed the framework for the panels and workshops in this conference because they are still widely manifest for people with disabilities. The report is divided into corresponding sections, each providing facts, proposals and opinions on how everyone who wants to bring about change – governments, international organizations, disabled people’s groups and individuals – can best address them.

And address them we must if the world has any chance of meeting the Millennium Development Goals, a set of minimum standards to reduce poverty and promote health, equality and sustainability, agreed by every country. Without the inclusion of people with disabilities in all social and economic development programs, such efforts can never fully succeed.
The work of our two organizations, the conference participants and you, the users of this report, is to translate the ideals of the UNCRPD into reality. Thank you for joining us and we wish you success in reaching our mutual goal.

Yours sincerely,

Thokozile Ruzvidzo
Officer-In-Charge
African Center for Gender and Social Development
UNECA

Hassan Musa Yousif
Focal Person on Disability, UNECA

Tanya Barron
International Director
Leonard Cheshire Disability
And special thanks go to...

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Ethiopian Airlines
The Ghion Hotel
The Bekele Molia Hotels Hiber Restaurant
Fiona McConnon, and staff team of Leonard Cheshire Disability: Sudhindra C N, Nicki Bailey, Rebecca Lee and Jenny Massey
Hassan Yousif and staff team of UNECA, ACGSD
Braille Transcriptions UK
Fikerte Abebe

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This report could not have been produced without the help of the many rapporteurs who donated their time and skills to take note of the discussions in the workshops and panel speeches. They are (in alphabetical order):

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### List of acronyms

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<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>AAL</td>
<td>Argentinean Accessibility Law</td>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>ARI</td>
<td>Africa Rehabilitation Institute</td>
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<td>AU</td>
<td>African Union</td>
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<td>AUC</td>
<td>African Union Commission</td>
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<tr>
<td>CAADE</td>
<td>Special Coordination of Support and Assistance to Persons with Disabilities</td>
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<tr>
<td>CAS</td>
<td>Country Action Strategies</td>
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<tr>
<td>CBM</td>
<td>Christoffel Blindenmission (Christian Blind Mission)</td>
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<td>CDPF</td>
<td>China Disabled People’s Federation</td>
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<tr>
<td>CEDAW</td>
<td>Convention on the Elimination of All Forms of Discrimination against Women</td>
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<td>CIL</td>
<td>Centers for Independent Living</td>
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<td>CRC</td>
<td>Convention on the Rights of the Child</td>
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<td>CWIQ</td>
<td>Core Welfare Indicator Questionnaires</td>
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<td>DFID</td>
<td>Department for International Development of the UK</td>
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<td>DHS</td>
<td>Demographic and Health Survey</td>
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<td>DPOD</td>
<td>Disabled People’s Organization Denmark</td>
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<td>DPO</td>
<td>Disabled People Organization</td>
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<td>DSC</td>
<td>Decade Steering Committees</td>
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<td>EA</td>
<td>Enumeration Areas</td>
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<td>EMIS</td>
<td>General Educational Management Information System</td>
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<td>EU</td>
<td>European Union</td>
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<td>GDP</td>
<td>Gross Domestic Product</td>
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<td>GEQIP</td>
<td>Education Quality Improvement Package</td>
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<tr>
<td>GPDD</td>
<td>Global Partnership on Disability and Development</td>
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<tr>
<td>GTZ</td>
<td>Deutsche Gesellschaft fuer Technische Zusammenarbeit (German Society for Technical Cooperation)</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>HLCS</td>
<td>Household Living Conditions Surveys</td>
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<td>ICF</td>
<td>International Classification of Functioning</td>
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<td>ICT</td>
<td>Information and Communications Technology</td>
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<td>IFRTD</td>
<td>International Forum for Rural Transport and Development</td>
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<td>ILO</td>
<td>International Labour Organization</td>
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<tr>
<td>IMF</td>
<td>International Monetary Fund</td>
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<tr>
<td>IT</td>
<td>Information Technology</td>
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<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>LLRD</td>
<td>Linking Relief, Rehabilitation and Development</td>
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<td>LSM</td>
<td>Living Standards Measure</td>
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<td>MDG</td>
<td>Millennium Development Goal</td>
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<td>MFIs</td>
<td>Microfinance Institutions</td>
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<td>MICS</td>
<td>Multiple Indicators Cluster Survey</td>
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<tr>
<td>MP</td>
<td>Member of Parliament</td>
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<td>MUCCoBS</td>
<td>Moshi University College of Cooperative and Business Studies</td>
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<tr>
<td>NADAWO</td>
<td>Namibian Association of Differently Abled Women</td>
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<td>NAPC</td>
<td>National Anti-Poverty Commission</td>
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<td>NCPEDP</td>
<td>National Centre for Promotion of Employment for Disabled People</td>
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<td>NCPWD</td>
<td>National Council for Persons with Disabilities</td>
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<td>NEPAD</td>
<td>New Partnership for African Development</td>
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<td>NGOs</td>
<td>Non-Government Organizations</td>
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<td>NICI</td>
<td>National Information and Communication Infrastructure</td>
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<td>NRM</td>
<td>National Resistance Movement</td>
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<td>NSO</td>
<td>National Statistics Office</td>
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<tr>
<td>OECD</td>
<td>Organization for Economic Cooperation and Development</td>
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<td>OHCHR</td>
<td>Office of Higher Commissioner for Human Rights</td>
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<tr>
<td>PhilCOCHED</td>
<td>Philippine Council of Cheshire Homes for the Disabled</td>
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<tr>
<td>POETA</td>
<td>Partnership in Opportunities for Employment through Technology in the Americas</td>
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<tr>
<td>PRBS</td>
<td>Poverty Reduction Budget Support</td>
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<td>PRP</td>
<td>Protracted Relief Programme</td>
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<td>PRSPs</td>
<td>Poverty Reduction Strategy Papers</td>
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<td>PWD</td>
<td>Persons With Disability</td>
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<td>RBM</td>
<td>Result Based Management</td>
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<td>SAFOD</td>
<td>Southern Africa Federation of the Disabled</td>
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<td>SEDESE</td>
<td>Minas Gerais’s State Bureau of Social Development</td>
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<td>SIDA</td>
<td>Swedish International Development Cooperation Agency</td>
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<td>SINE</td>
<td>National System of Employment</td>
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<tr>
<td>SWAp</td>
<td>Sector Wide Approach</td>
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<td>TQSI</td>
<td>Ten Questions Screening Instrument</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<td>UN</td>
<td>United Nations</td>
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<tr>
<td>UNCRPD</td>
<td>United Nations Convention on the Rights of Persons with Disabilities</td>
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<tr>
<td>UNDESA</td>
<td>United Nations Department for Economic and Social Affairs</td>
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<tr>
<td>UNDP</td>
<td>United Nations Development Programme</td>
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<tr>
<td>UNECA</td>
<td>United Nations Economic Commission for Africa</td>
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<tr>
<td>UNESCAP</td>
<td>United Nations Economic and Social Commission for Asia and the Pacific</td>
</tr>
<tr>
<td>UNESCO</td>
<td>United Nations Educational, Scientific and Cultural Organization</td>
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</table>
UNICEF  United Nations International Children’s Emergency Fund
UPE    Universal Primary Education
USA    United States of America
USAID  United States Agency for International Development
USE    Universal Secondary Education
WG     Washington Group
WHO    World Health Organization
WSIS   World Summit on Information Technology
A global conference for action:
preface to the conference report

These are the proceedings of a global conference on disability, jointly organized by UNECA and Leonard Cheshire Disability, under the theme of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD): a call for action on poverty discrimination and lack of access. The UNCRPD was drafted with unprecedented speed and participation by people with disabilities, who are its new stakeholders. Ratification has also taken place more quickly than anyone could have predicted, showing a high level of commitment from both governments and the civil society organizations that lobby them.

The conference was held from 20 to 22 May 2008 – 17 days after the UNCRPD came into force on 3 May. The closeness of these two events was coincidental, as preparations for the conference started two years earlier. The conference drew 500 participants and speakers from 58 countries. Persons with disabilities, disabled people’s organizations (DPOs), service providers, representatives of government, the African Union Commission, UN agencies, the World Bank, and international and national NGOs attended the conference.

Drawing on the mandates, comparative advantage and resources of UNECA and Leonard Cheshire Disability, the conference was very successful in directing attention to disability in the world. As the premier regional organization, UNECA\(^1\) brought governments from throughout the continent to the conference, and provided valuable substantive and logistical support and conference facilities. Leonard Cheshire Disability\(^2\) provided funds and brought civil society and people with disabilities from all over the world to the conference. It celebrated its 60th anniversary in 2008.

Teamwork and cooperation between UNECA and Leonard Cheshire Disability demonstrate the need to initiate and consolidate partnerships to successfully implement the Convention. Indeed, the momentum and inclusiveness that marked the formulation of the Convention must equally be matched with intensive implementation activities at all levels. This momentum has been the main driving force behind the success of the conference, which provided a global platform for showcasing successes, identifying common challenges and lesson learning across the continents. The main challenge now is to take action and implement the changes needed to ensure that persons with disabilities have full and equal enjoyment of all human rights.

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\(^1\) UNECA celebrated its 50th anniversary in Africa in 2008

\(^2\) Leonard Cheshire Disability is the secretariat for a Global Alliance of disability organizations throughout the world, with three regional offices in Africa. It celebrated its 60th anniversary in 2008.
From the start to the end, the word “action” echoed most frequently throughout the conference; in the opening speech of the Ethiopian State Minister of Labor and Social Affairs, Mohammed Mealin Ali; in the subsequent eight keynote speeches; and in the Government Panel, which included China, Philippines, Kenya, Malawi, Uganda, South Africa, Ethiopia, UNDESA and OHCHR. Peter Ackroyd, Country Director of DFID, explained that the word “action” practically means “walk the talk” – in other words, make our actions match our words. This message guided the participants in 11 panels and 33 workshops on poverty, discrimination and access. They looked for good practice and identified strategies for both concerted action and effective implementation of the UNCRPD.

A pre-conference workshop was held on 19 May. It focused on actions relating to data and statistics in disability. The workshop provided a forum for policy makers and academics to explore the actions needed to address data and statistics limitations, and the paucity of research on persons with disabilities. During the conference’s panels and workshops, young people with disabilities from 18 countries called for actions to implement the articles of the convention at all levels. The closing ceremony focused on key action points for successful implementation of the Convention. This report gives an overview of all of these key points, with an emphasis on the practical actions that everyone present at the conference and every reader can take to promote the signing, ratification and implementation of the UNCRPD.
The urgency of now: an introduction

“A paradigm shift,” “a new language of disability,” “the world’s newest human rights tool.” These are a few of the messages about the genesis and impact of the UNCRPD that emerged from the conference. “I’ve been here before,” began conference keynote speaker Maria Verónica Reina, Executive Director of the Global Partnership on Disability and Development, a World Bank initiative. Ms Reina was speaking not of coming to UNECA, since this was her first visit, but of her feelings of exclusion. She had first felt this way growing up in a poor family in Argentina, who lived with a strong sense of class that gradually faded as her parents earned more money during her adolescence.

Then at 17 she was in a car accident and began using a wheelchair. Suddenly, she knew again what it was like to face discrimination. What changed was not just her physical circumstances, but also other people’s attitudes to them and to her – the definition and consequence of discrimination.

“Poor people and people with disabilities face similar issues,” said Ms. Reina, and the UNCRPD should draw a line between the past approach, when these issues were handled by charities, and the rights-based agenda of the UN Convention. If she could, Ms. Reina would have the world’s leaders write the phrase “paradigm shift” on a blackboard 100 times.

“It will be a challenge for people with disabilities to recognize that we have rights and responsibilities,” Ms. Reina said. Provisions within the Convention say that states should not deprive people of liberty based on disability, which will be a task for both governments and for the institutions and people that they govern. For this reason, the delegates who wrote the UNCRPD felt that this provision must be adopted immediately.

“Disability is a force for inclusive development, not a burden on development activities” – so contends Dr. Hassan Yousif, focal person on disability, UNECA. Dr. Yousif reminded the conference that the rights contained in the UNCRPD are embodied in the Universal declaration of Human Rights. “The UNCRPD officially offers no new rights,” said panel speaker Barbara Murray of the International Labour Organization. Instead, it offers innovations in how people with disabilities may access the full range of existing rights that are already protected by international law, for instance in the areas of gender, children’s rights and the inclusion of ethnic minorities. Notably, the language of the Convention is totally different from much of the previous legislation on disability. The word “special” is never used in the document and the focus is on the right to full participation in all aspects of society.

The document also makes provision for changes in the way that disability is handled both legally and practically. For example people with disabilities, even those in
sheltered workshops, now have the same rights as any workers to form unions, to benefit from equal opportunities, to be included in affirmative action programs and to qualify for work experience programs.

People with disabilities also have the same rights as other people to have relationships and families, to get married and not to be sexually harassed. Disabled children have the right to attend school and their families have the right to take part in any anti-poverty programs, including those designed to meet the Millennium Development Goals (MDGs) by 2015.

There is now not one sphere of life in which disability should hinder full participation. To make this happen, a “no-gap” policy is essential, said Vittoria Beria from the United Nations Department of Economic and Social Affairs. Such a policy means that no element or part of the Convention can be implemented without involving more than one issue or sector such as access, legal representation or education – all its work must be done on a continuum.

The need to make active links with and learn from other areas of development and human rights practice – gender equality, children’s rights and the inclusion of ethnic minorities, for example – was also highlighted at the conference. Thokozile Ruzvidzo, Officer In Charge, African Centre for Gender and Social Development, UNECA, pointed out that implementation and its evaluation can be challenging processes that require enormous political will from governments. If we look to disability rights as a force for inclusive development, then the whole process of bringing the Convention to life can become embedded in every local, national and international development initiative.

Almost 80% of people with disabilities live in developing countries, according to Sadequa Rahim from the African Union. Disabled people, therefore, must be involved in poverty reduction strategy papers and national frameworks, especially women with disabilities, who can face a double burden of discrimination. She highlighted the link between the AU Plan of Action on the Decade of Disabled Persons and the UNCRPD. It follows that disabled people with knowledge of human rights should be involved in their own governments’ planning and implementation processes for the UNCRPD. This point was made by speakers living as far away from each other as Josephine Sinyo from the Kenyan Law Reform Commission and Manuel Agya, a congressman from the Philippines.
Making development truly inclusive will enrich the world for everyone, argued Bryan Dutton, Director General of Leonard Cheshire Disability, yet it would be tragic if new initiatives don’t include people without disabilities. Inclusive development must be exactly that.

Mainstreaming arises from this premise, and for non-disabled people, it has an important role to play in ending the ignorance about disability that can lead to exclusion. For people with disabilities, argued Eva Mahlangu from the South African President’s Office, it yields feelings of dignity and self-worth. To make mainstreaming a priority for all government departments, she further argued, it must be included in all budgets and monitoring exercises.

Many African countries already take progressive steps towards bringing disability into national institutions and programs. In Uganda, for example, there are already five disabled members of parliament, one of whom is a woman. New laws also state that new buildings must be accessible. Kenya already enacted a Disability Act in the 1990s and has drafted an inclusive education policy. Malawi, which has signed but not yet ratified the UNCRPD, has already held a public consultation on disability.

To go beyond these first few steps, conference delegates agreed that they must stop talking just to themselves – the disabled community and its allies. Many speakers and participants also called on everyone present to lobby their governments to ratify and implement the UNCRPD. Making this effective, they noted, will take cooperation between civil society and governments, between people with and without disabilities and between multilateral and national bodies.

As Bryan Dutton commented, “nothing will be gained by people sitting in rooms talking about ideals. On the other hand, nothing important starts without it.” The conference delegates can now take the ideals and innovations expressed at the conference to as wide an international audience as possible. As Mr. Dutton concluded, “Martin Luther King spoke of the ‘urgency of now’. Let’s take this forward today.”
1. Setting the scene: an overview of the change to come

“Exclusion is often based on ignorance rather than antagonism.”
Bryan Dutton, Former Director General, Leonard Cheshire Disability

The conference played a major role in promoting the understanding that can lead to genuine change. Those who attended and took away new ideas or techniques, and those who will learn more by reading this report, have joined the movement to bring disability to the forefront of debate within the world’s governments, international institutions and civil society organizations. Learning truly dispels ignorance.

Since the conference’s purpose was to promote this debate and exchange of ideas, the first day’s speakers introduced the overarching themes that frame discussions on the full inclusion of people with disabilities. Panelists came from a wide range of countries and organizations, reflecting the fact that there is no area of life in which disabled people should not fully participate.

Opening remarks
Mohammed Mealin Ali, State Minister of Labor and Social Affairs, Ethiopia

In declaring the conference officially open, Mohammed Mealin Ali spoke of our host country and explained that people with disabilities represent perhaps 10% of Ethiopia’s population, or approximately seven million people. Despite this relatively large number, people often face exclusion within the country just because of their disability. This may have several manifestations:

1. Children with disabilities may not go to school
2. Women with disabilities can face a double burden of discrimination
3. People with disabilities are more affected by HIV/AIDS
4. There is a general lack of access throughout society.

This means, he asserts, that people with disabilities must get special recognition within governments. Since Addis Ababa is the seat of the UN in Africa, it will help ensure that the process of implementing the UNCRPD, which Ethiopia signed in March 2007 in New York, will be transparent and fully inclusive. Mr. Ali pledged his support to encouraging the government of Ethiopia to ratify the Convention, and hoped that the conference would help make this happen.
Keynote speakers

a. Using the UNCRPD to reduce poverty and achieve economic empowerment
Maria Verónica Reina, Executive Director, Global Partnership on Disability and Development, the World Bank

Ms. Reina began her presentation by admitting that she felt very emotional. Her journey, she said, had been interesting not just because this was her first trip to Ethiopia and to Africa, and she was meeting colleagues she had only met online before, but also because of the huge step forward that the UNCRPD represents.

Many people attending this conference actually worked on the UNCRPD and, as Ms. Reina is not a legal expert, she focused on transmitting what people with disabilities want from it. First and foremost, the priority is to draw a line under the patriarchal charity approach of beneficiaries and donors and move on to a rights-based agenda. It is time to move past the common disability models – such as the medical or even the social model – she asserted, because they are based on theories and logic, but do not necessarily reflect people’s everyday experiences.

The UNCRPD was drafted with the unprecedented participation of people with disabilities, who are now its stakeholders. If she could, Ms. Reina would have world leaders write on a blackboard 100 times the words “Paradigm Shift.” This is necessary even, and perhaps especially, within the world’s corridors of power, because even a modern, inclusive building such as the UNECA conference center (where the conference was held) has disabled accessible toilets, but no ramp to the speakers’ podium. Ms. Reina, a wheelchair user, was thus forced to speak from the conference floor. “People with disabilities can be speakers as well as participants,” she reminded everyone in the room.

This leads directly to the UNCRPD provision that no state should deprive a person with a disability of his or her liberty. Institutions therefore need to change to help people with disabilities achieve parity with other citizens. Delegates working on the Convention felt that this provision above all should be implemented immediately.

The counterpoint to this is that people with disabilities themselves need to recognize that they have rights and responsibilities. The many people who created the UNCRPD are all different actors with different roles. By working within their own societies, they can change attitudes and help bring equality to disabled people in this new century.

b. Disability and inclusive development in Africa
Sadequa Rahim, The African Union Commission (AUC)

Ms. Rahim confirmed that the AUC’s social development agenda is also human centered, meaning that it affords all people, including those with disabilities, the opportunities they need. According to Ms. Rahim, almost 80% of the world’s people with disabilities live in
developing countries, yet disability is often perceived negatively. Disability can be left out of programs in disaster relief, poverty reduction and social inclusion, and even excluded in Poverty Reduction Strategy Papers (PRSPs). The principles of inclusiveness, she said, need to be built into all public programs and public buildings, including to:

1. Raise awareness
2. Identify obstacles
3. Monitor impact
4. Include all stakeholders
5. Respect human rights and differences as part of human diversity.

The AUC has taken specific actions to foster these goals. For instance, since the 1980s African heads of state and governments have addressed disability, which resulted in permanent African Rehabilitation Institutes (ARI). Launched in Harare, Zimbabwe, in 1988, there are now registered ARI offices in Zimbabwe, Congo and Senegal.

Above all, the African Union Commission adopted an African Decade of Persons with Disabilities from 1999 – 2009. This was later extended for another ten years. Covering a wide range of issues, the Decade also provides a framework for human rights among people with disabilities. Ms. Rahim pledges that the AUC will continue to mainstream disability among its programs and to use concerted effort to face the challenges that arise.

c. **Human rights are universal**
   
   Hassan Yousif, UN Economic Commission for Africa, Ethiopia

As a human rights document, the UNCRPD is not unique. So contends Mr. Yousif, who reminded the conference that all the rights contained in the Convention are already embodied in the Universal Declaration of Human Rights, which celebrates its 60th anniversary this year. The disability movement has also benefited from the human rights campaigns of other groups, including those that created the UN Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination against Women.

Yet we are still at the beginning of the process to achieve full human rights for disabled people. We still need the data to support our claims about poverty and discrimination and development partners must support data collection and analysis. Implementation is also a cumbersome process that requires a clear approach. Again, stakeholders must monitor the implementation process and evaluate its outcomes. Disability is a force for inclusive development, not a burden on development activities.

d. **Using the UNCRPD to promote decent work for persons with disabilities**
   
   Barbara Murray, Senior Disability Advisor, International Labour Organization, Switzerland

The UNCRPD heralds a new era in human rights for people with disabilities, and at the same time shifts the focus of debate, contends Barbara Murray. Officially, it offers
no new rights. Instead, it includes innovations in the way disability is considered and handled. For instance, there is no mention of the word “special” in the Convention. Denial of reasonable accommodation for work is implicit in the UNCRPD, and this is also new. Workers with disabilities now have equal legal protection to all other employees, including:

1. They may form unions on an equal basis, including those in sheltered workshops
2. All tools for promoting economic opportunities must be accessible
3. Affirmative action is permissible
4. States are called on to promote work experience programs
5. There can be no slavery or unpaid servitude.

Access to education is another important element of the UNCRPD that affects work. General tertiary education, vocational training, adult education and lifelong learning must all now be provided without discrimination and be accessible to disabled people on an equal basis with others. This includes access to mainstream vocational guidance, training and employment services, as well as vocational and professional rehabilitation services geared to entering and re-entering work.

To support this paradigm shift, fundamental changes are required, including in the roles of both specialist disability and mainstream agencies and service providers. All social partners – employers, trade unions, and civil society – will need to be involved, and certain types of services and programs, such as sheltered employment and vocational training, might need to change their emphasis considerably.

The future in the field of work and disability is now wide open. As it evolves, the ILO will continue to work with all special service providers and mainstream services. To facilitate this, they have developed varied materials that people with disabilities and employers can use to help implement the new Convention.

e. Access to relationships and family life

Rachel Kachaje, Deputy Chairperson, Disabled Peoples International

Ms. Kachaje has been an activist for a long time. She observed that many people do not believe people with disabilities should have relationships or families. The rights of disabled women, in particular, have been violated, and they may not even be perceived as women, just as disabled people.

The ignorance and negative attitudes responsible for this situation, she contends, spill over into other areas. For instance, people may assume that a man who marries a disabled woman is desperate. Or they may believe that women with disabilities are desperate for sex (presumably having been denied it because of their disabled status) and men may force sexual acts on women with the excuse that they are doing them a favor.
The birth of a child with disability can lead to divorce, and if the disabled child is a girl, she may be sterilized. Sometimes relatives of disabled parents even take away their children in the mistaken belief that they cannot be adequate parents.

Knowledge of sexuality and physical changes often is not shared with disabled young people. For instance, a baseline study in South Africa found that most girls with disabilities were not told about menstruation by their parents, because it was assumed that they would not be sexual.

Sexuality is one of the most personal and private aspects of life, and is often misunderstood. The UNCRPD can help to bring the issue of relationships and family life out into the open and, as such, is a source of hope to people with disabilities. Now, said Ms. Kachaje, we need to take the UNCRPD’s words to the next level – action – to truly change the situation.

f. Inclusive education and the Millennium Development Goals
Augustine Agu, UNICEF Ethiopia

“If you share a school desk with a disabled person, you will discover his abilities and your own disabilities.” So began Augustine Agu in speaking about how the UNCRPD
will contribute to the second Millennium Development Goal (MDG) – universal primary education.

The goal of universal primary education is not new – it was declared in 1960. Since then people have been stuck and that is why we need the MDG, contends Mr. Agu. Inclusive education, in which children with disabilities learn in mainstream schools, addresses the needs of all learners and is necessary to enable all children to attend school. What is missing from the MDG, however, is the process by which the world will meet it.

About 10 to 20% of the world’s children are now not in school and we need to find out who they are. Often they are disabled and there are many factors that keep them out of the educational system, including fears by parents that they are too vulnerable (particularly the girls) and other barriers that have not been addressed. The so-called non-disabled children may not understand their disabled peers, Mr. Agu believes, but he also believes that it is fear that makes disability difficult to understand.

To even begin to meet the MDG for universal primary education, it will be necessary to start using the UNCRPD now. MDG targets can be structured in ways that enhance the rights of people with disabilities. For instance, all national educational plans should conform to standards that include children with disabilities. There is a national educational management information system (EMIS) in every country, and these should not be released unless they conform to disability concerns.

These and other policies must then be followed up by action for inclusive development. Through the implementation of the UNCRPD, inclusive development would be achieved and the paradigm shift from a charity to a rights-based approach would be achieved.

To make this happen in the education sector, it is also essential to develop tools for assessing and endorsing all education plans and budgets, to ensure that they include disability. Governments should also take responsibility for removing barriers to learning and school attendance. Finally, the urgency of achieving the MDGs through education requires economic and political action from all stakeholders.

g. Innovative solutions to provision of accessible transport to rural and hard-to-reach areas
   Marinke van Riet, Executive Secretary, International Forum for Rural Transport and Development (IFRTD)

   “It is not disability, but the system, which makes a person disabled.”
   – Vardhani Ratnala, Leonard Cheshire Disability, India, Participant in Mobility and Health Networked Research Programme

Starting her presentation with this quote, Marinke van Riet explored why the transport sector may be called the “missing link” in development. There are many reasons for this, including the fact that many people who work in transport are engineers and
technocrats who may not think of the social implications of the sector. The sector is also known for integrity and corruption issues, and in general many countries allocate disproportionate resources to road building because of its status or decision-makers’ prejudice about the best way to travel.

The IFRTD explores transport for a range of diverse groups including people with disabilities. It is hard to evaluate what is most and least effective within transport now, however, because there is very little data about whether transport currently meets the needs of people with disabilities. The network is trying to create more, but this will be a long process as they have been fighting for gender-disaggregated data for years, with mixed results.

One of the forum’s flagship current research projects is mobility and health, looking specifically at the relationship between access to maternity care and rural transport in 25 case studies in Latin America, Asia and Africa. The goal is to increase the understanding of the impacts of mobility constraints on access to (maternal) health of poor people, including vulnerable groups, and to develop an advocacy program to sensitize the health and transport sector to mobility and health issues. So far, preliminary analysis has found that because of distance and barriers such as rivers and mountains, most health services had no or low accessibility for people with disabilities. Some of the issues included:

1. Footpaths/steps unfavorable for wheelchair movements
2. No aids/appliances available for people with disabilities
3. Access infrastructure is not designed for people with difficulties
4. Badly maintained or non-existent rural roads
5. No ramps in public buildings for wheelchair access.

People with disabilities also often had low or no mobility to reach health services, and issues included:

1. Lack of regular and/or reliable rural transport services
2. No facilities for people with disabilities in the available transport, such as buses or trains
3. Overcrowded transport modes, both land- and water-based
4. No facilities such as ramps and landing stations to get on and off transport, even when required by law
5. No priority seats available in public transport services for people with disabilities, even when required by law
6. Rural transport operators refusing to accept people with disabilities.

In fact, the state of affairs in rural transport may exacerbate or even cause disability.

The third element of the problem is that there is often no policy enforcement, so that even when laws exist, they are ignored. The mobility needs of people with disabilities are often simply not even considered when transport is planned or constructed, and
there is no good cross-sectoral policy framework. For example, planning for the health sector does not include transport-related components and vice versa. What is the way forward? Ms. van Riet proposes the following:

More research needs to be done on inclusive transport and infrastructure in the rural context. The World Bank’s new Transport Business Strategy, bilateral organizations and governments have prepared inclusive Transport Guidelines – enforcement is lacking so there is a need for policy monitoring. A cross-sectoral approach between the transport and disability sectors is required if we want change.

There are also several regional networks being developed on transport and disability, and the South Asia office of Leonard Cheshire Disability may host one for that region. Many governments have transport policies, but their implementation is often very slow. To bring the goal of access closer to being realized, transport policy must include disability, and Ms van Riet called on everyone at the conference to make sure that this happens. The IFRTD will stand with you on this.
Questions to and answers from the panel

The opening speakers engaged in a lively debate to explore the finer points of the UNCRPD and its implications for the future. Points were raised in the following categories:

**African Decade of Persons with Disabilities**

The AUC is committed to the African Decade of Persons with Disabilities from 1999 – 2009 and it will evaluate how well it has been implemented. It is the responsibility of member states to implement the decade and the AUC provides the framework.3

**Employment rights for people with disabilities**

It can be difficult to convince employers to hire people with disabilities, but there has been pioneering work done in this field by the Employers Federation of Ceylon. There is also an employers’ federation in the UK, set up by employers to look at these issues, particularly accommodation. In the coming months the ILO will release information on this approach for use by other employers.

There is a lot of experience in employment of people with disabilities in Europe, Australia and New Zealand, where the employment sector has been transformed. Other countries can look to their experience for guidance and ideas.

In small island states with correspondingly small economies, governments are moving away from service provision. In these countries, people with disabilities may rely on sheltered workshops for employment. Even in these cases, governments may be able to adopt tried and tested approaches to stimulating employment for disabled people in the private sector from larger nations, as above.

**The UNCRPD and human rights**

Although the UNCRPD does not offer new rights beyond those of the Universal Declaration of Human Rights of 1948, it is definitely not business as usual. It does include specific provisions on rights to employment, education and other fields. Some policy makers may now want to change their existing attitudes about disability. The implementation of the UNCRPD will compel them to do so.

**Inclusive education**

There is now an effort being made to ensure that the number of children with disabilities is included in UNICEF education reports in Uganda. This had not been done earlier and
this problem extended to other issues, such as malnutrition and children affected by conflict.

In South Africa, there are challenges in implementing the inclusive education policy in the field, but they are working towards shifting people’s awareness so that they can understand the value of teachers and other professionals adopting and implementing inclusive education.

**Accessibility in Ethiopia**

Recently the Ethiopian Ministry of Urban Works and Development created a building code that is still in draft form and will take access into account. The Ministry for Labor and Social Affairs also addresses inaccessibility of buildings and transport. Overall, the government is striving for a common consensus and a government statement on access.
2. Exploring policy and practice: government and multilateral organizations’ work in disability and development

A range of stakeholders developed the UNCRPD as an international Convention. Ultimately, its implementation will rest with each national government. The range of government responses to disability is as wide as the range of countries in the world.

When a government has particularly successfully approached disability legislation in the past, it can offer this experience to other countries as a model that can be adapted to meet local needs and conditions. With this in mind, speakers from several multilateral and government organizations shared their input into the process of changing disability legislation, and creating more inclusive societies.

a. The UNCRPD: its implementation and the support of the UN

Vittoria Beria, Social Affairs Officer, Department of Economic and Social Affairs (DESA), United Nations Secretariat

Vittoria Beria has taken part in negotiations around the UNCRPD since its beginning, and has supported the participation of non-governmental organizations in the process. From this point of view, she believes that the goal of reducing poverty was a catalyst for the Convention, as the president of Mexico introduced the idea of a Convention in 2002 saying that poverty could never be overcome without addressing disability.

For the first time in the formulation of a UN Convention, governments and civil society delegates, with unprecedented participation of people with disabilities, conducted UNCRPD negotiations. It also had a very quick passage in UN terms.

An important element of the UNCRPD is its no-gap policy, meaning that no part of the Convention can be achieved without involving more than one issue or sector. Implementation cannot be mono-sectoral – all work must be done on a continuum.

Development is completely intrinsic to the Convention itself, and so Ms. Beria asked all conference participants to get out and speak to development actors. This includes NGOs, donors, multilateral organizations and others. It will now be much easier for them to run inclusive development programs with this new inclusive Convention.

On 3 May 2008 the UNCRPD entered into force, as 20 countries had ratified it. At the time of her speech only 17 days later, 26 had ratified. At the time that this report was written,
the number had grown to 46 and continues to rise. The time for implementation is now, Ms. Beria contends. Let's take this momentum and carry it forward into truly inclusive international development programs.

b. Persons with disabilities, the international human rights system and the role of OHCHR
Patrice Varhard, Office of the High Commissioner for Human Rights

Mr. Varhard opened his presentation by saying that, based on what he had heard in the morning, he would feel sorry if he were representing a country that had not yet ratified the Convention. As a representative of a multilateral organization, he proposed that we must challenge ourselves to change attitudes. From the first sessions, Mr. Varhard learned:

1. Disability is not inability – we should acknowledge that poverty, discrimination and lack of access are the cause of the problems
2. We must change attitudes rather than blaming the victims of the human rights abuses
3. If we only speak to ourselves, nothing will happen.

At the time of the conference, only seven African countries had ratified the UNCRPD. “Please,” he asked, “would all African representatives here commit themselves to their countries ratifying the Convention?” In order to do this, several steps must be taken:

1. Establish institutions responsible for implementation and monitoring, including policy review
2. Review the definition of people with disabilities within national legislation and consult with people with disabilities during this process
3. The framework for this should be national organizations within countries
4. Establish a task force on implementation with governments and multilaterals.

c. The life of people with disabilities in Ethiopia
Assefa Ashengo, Department for Labour and Social Affairs, Ethiopia

One salient feature of life for people with disabilities in Ethiopia, believes Assefa Ashengo, is that there is a serious lack of reliable data on disability. This situation is especially severe for mental disability, and little is known about mental health issues in Ethiopia.

The only current source of information is the national housing and population census (1994), and the last survey reported that there are one million people with disabilities out of a total population of 63 million. Unfortunately, these figures were almost certainly an underestimate for several reasons. For instance, homeless people were not included, and some families did not want to admit to having a disabled child because of presumed social stigma.

The World Health Organization, on the other hand, estimates that 10% of the world’s population is disabled, which would mean that Ethiopia could have up to seven million
people with disabilities. People with disabilities in Ethiopia are subject to isolation, discrimination and other barriers. Buildings are often not accessible and there are barriers to communication for deaf and speech-impaired people. Many people with disabilities live in rural areas that are not reached by services. In any case, there are very few government services that really address the needs of disabled people.

On the positive side, the Ethiopian constitution does include provision of services for people with disabilities. To develop this further, the government needs:

1. Development of social welfare policies
2. Support for the right of people with disabilities to employment
3. National health policies and education and training policies.

A national plan of action for the rehabilitation of people with disabilities would also be useful. There are several issues now facing the Ethiopian government regarding ratifying the UNCRPD:

1. The Convention has been submitted to the Council of Ministers and the current ministers are addressing issues. Recommendations include:
   a. To conduct awareness-raising
   b. Include disability in all policies and revise old policies
   c. The importance of international support.
2. Cooperation – international organizations and all disability/development actors should unite to implement the Convention
3. People with disabilities must be involved at all levels.


d. The situation of people with disabilities in South Africa

Eva Mahlangu, Office of the President, South Africa

Mainstreaming, believes Eva Mahlangu, equals dignity and self-worth for people with disabilities. It must, therefore, be part of all development activities. It also needs to be considered by all of a government’s departments and have its own budget allocation and monitoring.

Ms. Mahlangu believes that all governments should be committed to mainstreaming, and reported that the government of South Africa has shown their commitment to the idea. In 2005, the cabinet issued a directive to review the Integrated National Disability Strategy, 1997 (INDS). This policy was then released in 2007, taking into consideration updated policies, legislation and protocols as well as the impact of a changing and progressive international context on disability in South Africa. At the same time, South Africa recognized the value presented to the country in the UN Convention on the Rights of Persons with Disabilities and identified that the Articles of the Convention will guide government’s response to achieving an inclusive society in the review process.

South Africa has ratified the Convention and the Optional Protocols, and believes that implementation will enhance equality among all people. A national coordination board sits in the President’s Office to monitor the work of the government and NGOs on
issues related to disability, including budget allocations. Each government department also has a referral person/coordinator for disability issues.

At the highest levels, every government minister is responsible for progress on disability in his or her department and reports on integration and mainstreaming within the ministry to the president, through the President’s Office on Disability. The government would also like to form partnerships with other states to work on strategies and procedures for implementation.

At the provincial level, there is a disability council that works in a similar way to the national coordination board in monitoring and integration of people with disabilities. Their focus is mainly on regional and local governments and on the lower level government positions.

Ms. Mahlangu offered the thought that the success of disability mainstreaming relies on how well the roles of all stakeholders are defined. Ministers, as one group of stakeholders, play a sector-specific role and each sector needs focal people as coordinators. These can include representatives from DPOs, human rights organizations, parliamentarians and businesses.

e. Uganda’s progress on disability: nothing for us without us

The Hon. Balyejjusa Julius,
Member of Parliament Representing Persons with Disabilities, Eastern Uganda Constituency, Republic of Uganda

Uganda has already made considerable progress in implementing the UNCRPD and on other laws relating to people with disabilities. Unfortunately, before the National Resistance Movement (NRM) government came to power in 1986, people with disabilities were not recognized at all by the government or even by the larger society. After 1986, people with disabilities began to advocate seriously for their rights.

During the constitutional review process initiated by the NRM, disability issues were seriously debated with all the lawmakers involved at that time. From that period affirmative action began in Uganda, which in turn strengthened the disability movement in the country. Uganda has already taken the following steps to bring the UNCRPD to life:

1. Uganda was among the first countries to sign the Convention
2. Uganda was also among the first countries to sign the Optional Protocol
3. The line Ministry has also written a cabinet paper which is before the Cabinet of the Republic of Uganda for Ratification of the UNCRPD4.

4 At the time of the conference, Uganda had not yet ratified the UNCRPD. It later ratified both the UNCRPD and its Optional Protocols on 25 September 2008 following a briefing to the government by Mr. Julius after he attended this conference.
In addition to progress on ratifying the UNCRPD, Uganda has made other progress on disability issues. This includes involving people with disabilities at all levels within the government of Uganda – from village level to parliament – which believes in the phrase “nothing about us without us.” This includes representation by disabled people on all statutory bodies and commissions.

There is also a Minister responsible for disability affairs, and desk officers in the Office of the President and Vice President, also responsible for disability affairs. The Government of Uganda enacted “The Persons with Disabilities Act 2006” through the parliament, and since this preceded the UNCRPD of May 2007, it is an indication that Uganda is ahead of other countries in terms of championing disability issues.

On the economic side, the Government of Uganda is involved in the implementation of the “Prosperity for All Programme,” aimed at alleviating poverty among the Ugandan population. People with disabilities are stakeholders in this program and are being consulted on the best strategies for its implementation and monitoring, among other activities for income generation.

Looking at the social aspect, people with disabilities are given first priority when enrolling under the Universal Primary Education (UPE) and Universal Secondary Education (USE) programs. At both tertiary and university level, there are slots for people with disabilities under affirmative action.

Similarly, the government of Uganda has built four regional schools for special needs education and plans are underway for eighteen sub-regional special needs education schools. A full department in charge of special needs within the Ministry of Education underpins these initiatives. The government’s ministry of health follows a similar model, where there is a desk officer responsible for health matters relating to people with disabilities.

Because of the progress on disability rights that has already been made in Uganda, the country’s programs can serve as models for those of other states. Other countries are invited to look to Uganda’s example when implementing the UNCRPD.

f. Legal reforms in Kenya
   Josephine Sinyo, Law Reform Commission, Kenya

Josephine Sinyo, the only Senior State Counsel with a visual impairment and the first blind woman lawyer in Kenya, has been involved with the country’s disability movement for decades. Disability is not new as a political issue in Kenya: in the 1990s the disability act was passed and now disability is handled by the Ministry of Children and Gender. There is also an independent board, the Disability Council, which was established to oversee disability issues and programs within the country.
To bring the disability act to life, it was followed up with a draft national disability policy in 2007. Unfortunately, the document was not finalized within the expected timeframe because of the civil unrest in the country in early 2008, but it should be completed soon.

What are the aims of the Disability Act? Its goal is the provision of disability-friendly services in the country, including in health and education. A draft inclusive education policy is in the process of being formulated. It was also delayed by the communal violence, but once enacted will make education of children with disabilities central to government educational policy. Another goal of disability activists in Kenya is to amend the Kenya national constitution, which does not give disability a positive profile.

g. **Mechanisms to support people with disabilities in Malawi**

Felix Sapala, Ministry of Persons with Disabilities and the Elderly, Malawi

Malawi recognizes its responsibility in putting in place mechanisms to help people with disabilities to participate actively in society, and this is embodied in the Ministry of Persons with Disabilities and the Elderly, which was founded in 1998.

The government has already taken steps to sign and ratify the Convention. First it conducted a two-day consultation workshop in March 2008 that included disabled people’s organizations, service providers and a cross-section of other stakeholders. Everyone there agreed that the UNCRPD should be signed and ratified.

Clement Khembo, the Minister for Persons with Disabilities and the Elderly, signed the Convention in September 2007. To move to the next stage – ratification – a cabinet paper promoting the rights of people with disabilities was submitted to the Ministry of Justice. This is now in the final review stage at the ministry, which will then present it to parliament as a bill to be voted on by MPs.

The paper proposes that all government ministries allocate a budget for disability. In particular, the government will need to improve access to education and training, covering both more students and the types of courses available. Government ministries are also expected to look into structures within their programs that will equalize opportunities for people with disabilities.

The government of Malawi already intervenes in paying school fees for children with disabilities, because education will make their skills more attractive in the labor market. There is also a government campaign to encourage public and private sector employers to recruit disabled people, and the government has also increased small loan and microfinance programs that support entrepreneurs and small businesses run by people with disabilities.
h. The status of persons with disability in the Philippines
Manuel Agyao, Member of Congress, the Philippines

Approximately 82% of people with disabilities in the Philippines live in rural areas, where services may be less developed than those in cities, reported Congressman Manuel Agyao. People with disabilities are recognized within the Philippine constitution, which establishes a special disability agency. The Disability Act (1991), which was passed to improve the overall welfare of people with disabilities, further strengthened the situation. The government, as well as the NGO and private sector, remain committed to improving the welfare of people with disabilities in the country.

One manifestation of this is a wide program of vocational training centers around the country for people with disabilities. The program still needs to develop, however, because currently, resources to promote job placements that will accommodate everyone who is trained are limited. The government recognizes this and does recommend that employers in both the public and private sectors should employ more people.

i. Disability in China: the most populated country in the world
Ya’an Chen, Director, International Department, China Disabled People’s Federation, China

The China Disabled People’s Federation (CDPF) is China’s umbrella organization for people with disabilities and has approximately 30 million members throughout the country, equating to roughly 3.4% of China’s total population. Providing services to people with disabilities on behalf of the government is its primary role.

The history of the CDPF is linked to the world disability movement. During the 1980s, when the movement was active, the CDPF was also supported by the establishment of the UN Decade for Disabilities, which ran from 1983–1992. China is now examining internal policies and programs to review the status of people with disabilities in the country, in light of signing the UNCRPD. There are now four major disability programs in place in China:

1. A national survey on disability that started in the 1980s and is now published online
2. Revision of national laws that were completed and adopted in May 2007
3. Rehabilitation programs specifically designed for people with disabilities
4. Education programs to improve the educational experience of people with disabilities.
Questions to and answers from the panel

In **Uganda**, the National Union of Disabled People is the umbrella body that helps coordinate partners’ roles. 50% of its representatives are people with disabilities.

In **Nigeria**, banks are usually not accessible. People with disabilities demonstrated against this, which led to a riot. It was settled peacefully with the hope that new legislation on people with disabilities’ rights will cover the issue of accessibility in public buildings.

In **Kenya**, before the last elections, there was a cabinet paper prepared on the issue of inclusive education, but this was not carried forward seriously enough. Now there is a new disability minister – this post was only a month old at the time of the conference – and the Law Reform Commission of Kenya has already visited her. They aim to move together on all mainstreaming issues.

The number of children with disabilities in **China** has fallen. Mr. Chen’s personal opinion on why this has happened is that it is, in part, a result of China’s one child policy. Parents make sure that the mother has better prenatal care and better practices are followed during births. Iodine has also been added to salt in the country and medical services for pregnancy have improved overall. Other reasons, Mr. Chen believes, will emerge following academic study and analysis of the situation.

In **Uganda**, the special schools cater mostly for deaf and visually impaired students. Most public buildings now being constructed are accessible and plans are underway for provision of assistive devices. Sadly, budget constraints are the biggest challenge.

The Chair of the government panel, Peter Ackroyd, Country Director, DFID (Department for International Development of the UK), Ethiopia, offered the following suggestions for ideas that people might like to carry forward based on this session:

1. Should the ratification process be a target for all African nations?
2. Moving on to implementation, there is a feeling of a real sense of change. To make this happen, we need consultation and government commitment
3. A large number of agencies need to be involved
4. What we can all do is “walk the talk” – in other words, make our actions match our words
5. There is a big question of numbers here – people with disabilities in rural areas may be hidden
6. We must stop talking to ourselves and talk to the wider development community
7. The no-gap policy comes into the implementation process.
3. Poverty is a human rights issue

“Now we must take concrete steps to transform the vision of the Convention into real victories on the ground. We must deliver development that is truly for all.”
Ban Ki-moon, Secretary-General of the United Nations

“Addressing disability is a significant part of reducing poverty. Bringing disabled people out of the corners and back alleys of society, and empowering them to thrive in the bustling center of national life, will do much to improve the lives of many from among the poorest of the poor around the world.”
James Wolfensohn, former World Bank President, 2002

Poverty reduction is the world’s first priority. So say the Millennium Development Goals, which were agreed by every country in the world, and made halving the number of people living in extreme poverty by 2015 their first objective.

Examining how best to do this for disabled people was the complicated task of this conference. We know from the World Bank’s latest poverty statistics5 (August 2008) that the world is likely to meet this goal. But what do these broad measures really tell us about the relationship between poverty and disability and about the millions left living below the poverty line? Even the definition of poverty needs examination, contends panel speaker Charlotte McClain-Nhlapo of the World Bank. “Poverty is unique,” she said, “in being both an economic and human rights issue.”

Inclusive development means an increase in participation, access and representation by disabled people, as well as an increase in income. But it is important, she believes, for all disability stakeholders to recognize that to gain the full range of rights for people with disabilities, we must promote the economic rationale for poverty reduction. Without supporting a change in disabled people’s economic status, the necessary social change will not take place.

Two distinct approaches to how this might be done came up repeatedly in panel speeches and workshops:

1. Include people with disabilities in mainstream poverty reduction and social programs
2. Create other programs specifically designed for and targeted towards disabled people.

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Many maintain that both have a role in poverty reduction and that a synthesis of the two, known as the “twin-track approach,” is the best way forward. Mainstreaming and targeting need not work separately in any area of poverty reduction, argues panel speaker Sophie Mitra, who spoke in the context of including persons with disabilities in social safety nets. The same is true for job creation, according to Mark Palmer-Edgecumbe from Barclays Bank, who described a bank program that trains disabled people to work in mainstream job environments.

Again and again, poverty workshop speakers and participants emphasized that general poverty reduction programs may not meet disabled people’s specific needs. Classifying people with disabilities as a “vulnerable group,” for instance along with women or minority language speakers, can also create initiatives and policies that are too general to be useful.

The twin-track approach allows programs to be specifically designed for poverty reduction among people with disabilities. They can take particular needs, such as access, into account, which will then allow people to join mainstream initiatives. Its other component is targeting employers and governments to address issues within their reach, such as transport, equal opportunities policies and provision of disability equality training.

The workshops also emphasized important links between poverty and disability that can be different in different countries. Workshop speaker Dermot Foley explained how in Bangladesh, for example, poverty might be more closely associated with people who become disabled later in life, rather than those born with a disability. In several countries including Afghanistan, Zambia and Botswana, age rather than poverty was the strongest determinant of disability prevalence. Lack of education was also strongly associated with poverty among people with disabilities in many countries, illustrating the link between poverty of opportunity and economic deprivation, although not confirming which caused the other.
Treating all disabilities as equal in terms of their impact on poverty is also not the most effective means of bringing about change. For instance, in Bangladesh, research has found that people with ambulatory disabilities are three times more likely to remain economically active after becoming disabled than those with visual impairments. In other countries, visual impairment is associated with staying single, which can put people at greater risk of poverty in countries where marriage is nearly universal.

3.1 Panel presentations

Broadly considering the best ways to reduce poverty among disabled people, the four panel speakers on poverty covered initiatives by multilateral organizations, governments and the private sector:

3.1.1 Writing an “economic constitution”: inclusion of people with disabilities in national poverty reduction strategies
Charlotte McClain-Nhlapo, Senior Operations Officer, World Bank

The IMF and World Bank introduced Poverty Reduction Strategy Papers (PRSPs) in developing countries in 1999. PRSPs can be viewed as a country’s “economic constitution,” setting basic development values, objectives, strategies and operational rules that are framed and supported by social consensus.

Poverty is unique in being both an economic and a human rights issue, with compelling evidence showing that conditions of poverty directly influence the incidence of disability. People with disabilities are often among the poorest and have little representation in the wider society. Legally, frameworks such as the Universal Declaration of Human Rights include full rights for people with disabilities because they address all citizens.

In practice, some of these rights need to be reinforced by the new impetus of the UNCRPD, which calls for shared responsibility among all stakeholders to address the negative impact of poverty on persons with disabilities. It also mandates adequate social protection and specifically refers to poverty reduction plans such as PRSPs.

PRSPs will be instrumental in meeting the MDGs, which cannot be met without the inclusion of disabled people. They can form operational frameworks for achieving the MDGs at a country level, and are becoming increasingly important policy instruments for development. As both a process through which civil society (including disabled people’s organizations) can participate in policy development and an instrument to align donor activities, PRSPs can be a tool to enforce and measure accountability. Keeping the creation and implementation of PRSPs participatory will be vital to their success.

To truly include people with disabilities, the people behind PRSPs will need to do things differently. This means including people with disabilities in all stages of design and
implementation, as was done in Tanzania, for example. In 2005, the country published its second PRSP and involved disabled people’s organizations during the review and formulation process, creating awareness of the PRSP process in the disability sector. Inclusion has also increased in other countries: in 2000 there were only three mentions of disability in PRSPs, but by 2003 there were 17. At this point, Tanzania’s final PRSP and those of other countries that have incorporated disability may be considered an improvement, but more work on inclusion is still needed.

To help make PRSPs more effective in addressing disability, Ms. McClain-Nhlapo called everyone concerned to take on the following principles:

1. Mainstreaming disability into PRSPs is not sufficient – words must be followed by actions
2. DPOs need to have staying power
3. All stakeholders need to create the demand for true inclusion
4. Those concerned must get involved and understand the process
5. Identify champions in government and work with them
6. Develop strategic alliances with other stakeholders for inclusion, such as those focused on women’s and children’s issues
7. Add the missing elements to the PRSPs.

Ms. McClain-Nhlapo believes that the application of the UNCRPD to the development process is likely both to reduce poverty and to promote wider social change. Without advancing the economic rationale for inclusive development, however, it runs the risk of being a paper tiger. Being committed to expanding the principles of inclusion throughout its work, the World Bank can promote the economic arguments behind them. The momentum for this that the UNCRPD creates will be crucial.

3.1.2 Social protection and the role of social safety nets in low income countries
Sophie Mitra, Assistant Professor of Economics, Fordham University, USA

Social safety nets can play a dual role in disability according to panel speaker Sophie Mitra: through mitigating the poverty associated with disability and, through improved services, limiting disability caused by accidents and other preventable causes. To reach the highest level of impact, Dr. Mitra argues, social programs need to adopt the twin-track approach and employ both targeted and mainstream initiatives. Social safety nets include social insurance programs, social assistance programs and in-kind transfers such as assistive devices – canes or crutches, for instance. While a country works towards a fully mainstreamed social system, targeting can fill in the gaps and speed up the process.

The advantages of this approach begin when targeted programs take the needs of both people with disabilities and their caregivers into account. Social benefits may not only improve their welfare, but may also increase their status and bargaining power.
within the household. The negative impact of this approach may show itself in higher administrative costs and increased bureaucracy, which could be beyond the capacity of some developing countries. Coverage may then become limited to only certain segments of the disabled population, for instance those who become disabled on the job, which can leave other disabled people in a more vulnerable position.

People who receive benefits may also be less likely to seek paid work, which can lead to greater segregation and will not necessarily benefit the larger economy. This approach can also reinforce stereotypes of disability and not lead to the overall economic empowerment of people with disabilities.6

Mainstreaming may offset these disadvantages, which can affect a large number of people with disabilities, promotes inclusiveness and can cost less than benefits. Effective mainstreaming takes time, however, and targeted programs can fill in the gaps until all services become fully inclusive. In this instance, poverty reduction is closely related to improving access in four areas:

1. **Physical accessibility**
   a. The built environment, including government facilities and transport systems
   b. The ability of social workers to visit persons with disabilities
   c. The ability of family representatives to apply for, enroll and receive benefits on behalf of a person with disability
   d. Removal of geographical differences in program coverage (by region or urban vs. rural).

2. **Social accessibility**
   To ensure that a program is socially accessible, one would need to address the following points:
   a. Is the program information available in different formats (such as Braille)?
   b. Is the program information delivered through different channels besides the government (media, community)?
   c. Do the attitudes of social safety net staff prevent or discourage access to benefits for persons with disabilities?
   d. Do some of the social safety net staff have disabilities?

3. **Inclusive program design**
   Social safety nets may be designed in ways that exclude persons with disabilities. To find out if this is the case, one needs to ask questions such as:
   a. Would people with disabilities have difficulty meeting some of the eligibility conditions?

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6 For a detailed look at the economic impact of disability benefit policies, please see the report of Daniel Mont’s presentation at the beginning of the Access Section of this publication.
When health, education and other services are not inclusive, how can conditional cash transfers (benefit payments), based for instance on fulfilling school and clinic attendance, be modified so that they can reach persons with disabilities?

4. Inclusive program evaluation
Program evaluations need to address the following questions:

a. What proportion of people with disabilities who are eligible to participate in the program, actually take part?

b. What are the profiles of participants with disabilities compared to people with disabilities who do not participate?

c. What poverty alleviation and reduction impact does the program have on persons with disabilities?

Overall, to be most effective in poverty reduction among persons with disabilities, social protection must follow a twin-track approach of providing targeted and mainstream programs. It is also important to dedicate efforts to the collection of disability data, so that program evaluations can be inclusive.

3.1.3 Poverty elimination through recruitment: a Barclays case study
Mark Palmer-Edgecumbe, Global Head of Diversity, Barclays, UK

“If I asked you to list ten things that Barclays is famous for, I am pretty sure that eliminating poverty would not feature on that list.” So began Mark Palmer-Edgecumbe of Barclays Bank, and he even wondered himself, he said, why he had been asked to speak at this conference on poverty elimination. But as he considered Barclays’ work around the world, he realized that he had a lot to say about how to recruit, train and employ people with disabilities in a way that makes economic sense for them and their employers.

Focusing on “Recruitment that Works,” one of the bank’s recruitment initiatives in the UK, Mr. Palmer-Edgecumbe explained that it was designed in collaboration with the Employers Forum on Disability in the UK, to bring long-term unemployed people with disabilities back into employment. Two brothers, Paul and John, form an interesting case study of how the project works.

In 2006 Paul and John, both of whom had been injured in active service following long military careers, were living on disability payments after leaving the army. They saw an advertisement for “Recruitment that Works” inviting people with disabilities to apply for work with Barclays at one of their UK call centers. The ad stated that they would be assessed for the job on their ability, rather than their disability, and so they applied to be customer service advisors.
Barclays then assessed them to see if they had the basic competence to do the job, which they had. At 48 and 58 years old, the brothers had not worked for five and 15 years, respectively. This had not been through choice, however – despite applying for many jobs, they never got past the first interview.

The program then spent the next six weeks coaching them in preparation for their interviews with Barclays – a process they call “work preparation.” Their interviews were successful, showing that the preparation had worked, and they then had two weeks of on-the-job work experience. After that they had a final assessment and they were both successful in this as well.

Paul and John were two of 18 disabled people who started the program, and 13 who made it to the final interview stage. All 13 were offered jobs, beating Barclays’ own target of recruiting five long-term unemployed people with disabilities.

Barclays then wanted to maintain the level of support the trainees had received once they started employment with the bank. They trained every single member of staff at the call centre – some 300 people – in disability confidence, including the security guards and catering staff who were not even their own employees. When Paul and John started their jobs, they were also allowed to work part time until they were confident in their new roles.

All of this sounds very positive, and it is, believes Mr. Palmer-Edgecumbe, but Barclays believes that “Recruitment that Works” will only be successful over time if it is part of a holistic disability strategy. In Barclays’ case, this starts with leadership from the very top of the company, the Chief Executive, John Varley, who is their disability champion and, coincidentally, is also the President of the Employers Forum on Disability.

The bank’s strategy is to understand that reasonable adjustments are key. A centralized and centrally funded reasonable adjustments scheme ensures that it is as easy for line managers to recruit and develop a disabled individual, as it is a non-disabled person. They also maintain a disability helpline as the first port of call for help, support and advice for disabled employees and their line managers. In addition, all Barclays’ policies, practices and sources of help and advice are available from their Disability One Stop Shop – an intranet portal that tailors the information according to whether you are a disabled worker, line manager or co-worker of a disabled individual.

There is also mandatory training in disability confidence for all line managers and everyone who works in recruitment. To tackle issues and learn from people’s day-to-day experiences, the Chief Executive hosts two “Disability Listening Groups” a year, in which he checks in with disabled staff, ensures that the strategy is working and takes any necessary actions to adjust it.

From the bank’s point of view, this amounts to getting the basics right, which helps ensure that disabled employees contribute fully to the organization. Equally important is that
they also have the possibility to realize their own potential, and Barclays has established a global disability mentoring scheme through which every disabled employee who would like one, has access to a trained mentor.

So, from the point of view of Paul and John and Barclays’ other disabled employees, they have been lifted out of poverty by the “Recruitment that Works” program. From Barclays’ point of view, as a commercial company, why should it spend so much time and effort to recruit disabled people, when it could just recruit young people finishing schools and universities?

The answer is that, in addition to doing something positive for people with disabilities, there is a genuine business benefit to focusing on ability. Barclays started “Recruitment that Works” seven years ago at a different call centre, where they recruited 11 disabled people. Today, all of those individuals are still employed at that call centre and they are all top performers, highly motivated and also great ambassadors for Barclays.

Their high performance, low turnover and low absenteeism is something unheard or even undreamed of in the high turnover world of call centers. “Recruitment that Works” has become a project that makes good economic sense for Barclays, and for the disabled employees.

Since Barclays has done this and knows it works, the next challenge is for everyone at the conference to do something similar. Taking forward the spirit of this project, it is obvious that eliminating poverty is not just about giving someone money. It is also about providing a real job in mainstream society that can help provide dignity and self respect, and counteract feelings of worthlessness. And about Barclays’ role in this process, Mr. Palmer-Edgecumbe is very proud.

### 3.1.4 Strategies for reaching the poorest of the poor: the role of the African Decade

A.K. Dube, Head of Secretariat, African Decade, South Africa

Poverty remains a central concern of the African Decade of Persons with Disabilities, which was proclaimed by the African Union for the period 1999 – 2009, and extended to run for another decade in 2008. Managed by a Secretariat based in South Africa, its activities empower governments, NGOs, DPOs and development organizations, to include disability and persons with disabilities into policies and programs in all sectors of African society. Capacity building, advocacy, lobbying, coordination, monitoring and reporting are all part of the Decade’s agenda.

Like the other speakers on poverty, Mr. Dube highlighted the fact that poverty for people with disabilities may include high levels of unemployment, poor health and lack of access to services, education, infrastructure and rehabilitation support. All of this
leads to restricted prospects for individuals, a negative impact on whole economies and entrenched negative attitudes towards disability.

Because so many stakeholders are involved in the African Decade, the Secretariat works as a facilitator rather than an implementer. One of their main roles is to work with governments to develop models of work, advocacy and implementation that can be replicated in different countries. These models can then lead to country-level mainstreaming strategies and the development of indicators in all government sectors.

The other side of this approach involves strengthening the capacity of non-governmental organizations in planning programs and running their programs efficiently. Within this, the Decade particularly mobilises under-represented disability groups, such as women with disabilities and disabled youth.

Supporting the ratification and implementation of the UNCRPD is another focus, and the Decade’s strategy is to facilitate the participation of people with disabilities in country-level PRSPs and Country Action Strategies (CAS). This will feed into programs that help shape the policy and legislation environments within African countries, and facilitate mainstreaming of disability in all sectors, particularly HIV/AIDS. To help non-professionals understand the UNCRPD, the Secretariat is currently simplifying its language to make it more accessible to both persons with disabilities and others. A forthcoming law conference and a summer school on the new convention will also spread its message to a wide audience.

Touching on subjects covered by the other panel speakers, Mr. Dube explained how the Secretariat also called for people with disabilities to undertake accurate research into disability prevalence and social protection. This, he believes, will help unlock resources from governments and development organizations and create replicable models.

Working within the African Union and its constituent organizations, the Secretariat has a wide remit and opportunity to influence both policy and practice. It also attracts wide donor support, including from current funding partners Sida (the government of Sweden), DPOD Denmark, the Southern Africa Trust, DFID (the UK government) and CBM. Irish Aid and the EU are soon likely to support research.

The Secretariat also established decade steering committees (DSCs) in 20 countries. Each DSC should reflect the multi-disciplinary nature of disability and should be composed of representatives from government, DPOs, NGOs, the national AIDS council, media representatives, employers and trade unions. Working within the broad framework, the African Decade activities can reach as many people and organizations as possible, to decrease the poverty of people with disabilities.
3.2 Workshops

3.2.1 Disability must never again stand alone – Workshop 1: Mainstreaming disability to reduce poverty
Speakers: Teresa Mwendwa, Friends of the Disabled Federation, Kenya
Elisabet Eklund, UNDP, Kenya

“Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 or to give every girl and boy the chance to achieve a primary education, by the same date-goals agreed to by more than 180 world leaders at the United Nations Millennium Summit, in September 2000.”
James Wolfensohn, Former President, World Bank

Many contend that poverty is both a cause and a result of disability. Social stigma and lack of access to health, education and employment opportunities can lead to a vicious circle of reduced income and increased disability.

The basic needs of people with disabilities are the same as those for all people. In many countries, however, governments have set up structures to provide services for disabled people that run parallel to other government ministries or programs. Existing outside of the mainstream, these structures may never quite reach the majority of people with disabilities. In the main government ministries or departments, staff may not be sensitized to disability, or have the technical expertise and financial resources, to provide the necessary programs for people with disabilities.

The first workshop speaker, Teresa Mwendwa, proposed that the best way to overcome these problems is to mainstream disability into all sectors and in all development programs. This would include the full participation of people with disabilities, and supporting better research and data collection on disability and development. The UNCRPD provides a comprehensive framework on how to do this and enshrines disability issues in all programs: it can never again be thought of as standing alone.

The IMF and World Bank introduced PRSPs in 1999 in Africa, Asia, Eastern Europe and Latin America to form comprehensive country-based strategies for poverty reduction. Supporting the MDGs and addressing all aspects of development, they could be catalysts for involving people with disabilities in all socioeconomic development activities. They could also address the needs and participation of certain subgroups, such as women and children with disabilities.

Unfortunately, until recently few country PRSPs had a disability dimension, although the number is now increasing. Outcomes from proposed activities still vary, however, and PRSPs sometimes lump people with disabilities together with other “vulnerable groups.”
Experience has shown that when the specific causes of exclusion and the exact needs of people with disabilities are not explicitly identified, the resulting strategies and programs designed to address the “vulnerable groups” are likely to miss the differences in poverty determinants.

As the MDGs cannot be achieved without the participation of people with disabilities, disabled people’s contribution to PRSPs will be vital. One means of participation is through DPOs, which will need to involve themselves in all elements of the PRSP/development process, rather than waiting to be asked. Each PRSP addresses several issues that are particularly relevant to people with disabilities and in which they can make a large contribution: health and rehabilitation, education, infrastructure (which is particularly relevant to disability in terms of access issues) and employment.

Having emphasized that disabled people’s organizations must push for involvement, Ms. Mwendwa also pointed out that those preparing the PRSPs need to take disabled people’s needs into account. These could include presenting materials in alternative formats, considering physical access to meeting spaces and inviting people in advance so that they can make appropriate travel arrangements.

Turning specifically to Kenya, the second speaker, Elisabet Eklund, shared that Kenya won the UN’s Public Service Award for implementing the Performance Contracting Process, which is part of the Results Based Management (RBM) introduced by the Public Sector Reform Programme. The Award was won for “Improved transparency, accountability and responsiveness in the Public Service” in 2007.

Introduced in 2004, the Public Service Reform and Development Secretariat coordinates all public service reforms and should improve the quality of government interventions. They have also written a new national strategic plan, which includes “Vision 2030,” a goal based on three pillars: economic, social and political. Persons with disabilities are covered under the social pillar, through special provisions for vulnerable groups.

In the same year, Kenyan public services also introduced RBM, which calls for a cultural and attitudinal change among all levels of civil servants. RBM contributes to the creation of a shared culture of values, a common understanding of competency development and building networks of colleagues throughout the entire public service. It also incorporates various management tools such as strategic plans and annual performance plans, which different organizations can use to analyze public policy through a disability lens.

All of this has also been embodied in Kenya’s Disability Act 2003, and reflects well in advance the issues from the UN Convention on the Rights of Persons with Disabilities, A World Bank study estimates the annual loss of global GDP caused by high rates of unemployment among people with disabilities at between US$1.37 trillion and US$1.94 trillion. This is the perspective through which the issue of a comprehensive poverty reduction strategy for persons with disabilities should be considered in PRSPs.
which Kenya ratified in June 2008. The Disability Act establishes a National Council for Persons with Disabilities (NCPWD), which consists of a maximum of 27 council members and a secretariat lead by a director.

The Public Service Reform and RBM offer several other areas for further studies in mainstreaming disabilities. The different tools used for RBM, such as strategic plans and annual performance plans from different organizations, could be analyzed through a disability lens. Also, service charters could be evaluated by relevant disability organizations.

In Kenya, these first steps towards mainstreaming are already paying dividends. A recent study found that only 8% of people with disabilities faced discriminatory attitudes from public authorities, which is much lower than anecdotal reports from other countries. The Disability Act also requires a 5% quote for employment of people with disabilities, which again is higher than similar figures in other countries.

To help promote mainstreaming in government, donor and multilateral programs in all countries, workshop participants called for:

1. Wide stakeholder consultations in all development and government activities
2. Training for government ministers in disability issues
3. The UNCRPD could be used as a tool to mobilize resources for mainstreaming and the training and sensitization that will lead to it.

3.2.2 First steps towards preparing for work — Workshop 2: Microfinance is not the tool to reach the poorest of the poor

Speakers: Enzo Martinelli, International Disability and Development Consortium Livelihoods Task Group Leader, UK
Marinke van Riet, Executive Secretary and Director, International Forum for Rural Transport and Development, UK

Microfinance provides small loans and other small-scale financial services that allow poor people to start or improve small businesses. Typical microfinance programs provide access to capital for those who may be excluded from the formal banking sector, including some people with disabilities. This kind of program may not include other financial products, such as savings groups or financial training.

Such programs have been effective for people who have the skills, experience and personality traits to make their businesses viable, and the financial acumen to manage their loans. Most likely, they already have some training and experience in their field and in money management.

For the poorest people with disabilities however, using microfinance as the only tool to reach financial independence may be too big a first step. This is the conclusion
of Enzo Martinelli, who believes that more collaborative support programs from a range of service providers such as DPOs, NGOs and civil society groups can best meet this group’s needs. This is especially true for people who may also need help with practical issues such as access, transport and training. Skills development, increasing access to social protection, support for waged employment and savings groups are all appropriate interventions to consider for people with disabilities, who are just starting a transition into work.

Some specific activities that integrated projects can take to support people about to start small economic activity are:

1. Identify market-driven opportunities for small businesses that provide competitive advantages to people with disabilities
2. Research vocational training linked to marketable skills and marketable products among both services for disabled people and in mainstream training and business institutions
3. Adapt the vocational training curriculum to take into account disabled people’s access and other needs
4. Build self-confidence and provide career guidance for self-employment options
5. Facilitate peer support by successful entrepreneurs for people with disabilities.

Marinke van Riet also agrees that the small loans given by microfinance institutions may not work for the most vulnerable people. Instead, she advocates grants rather than small loans, which can help people with disabilities establish small businesses. In explaining how this is done through an NGO called Trickle Up, she pointed out that this approach also includes many of the services Mr. Martinelli mentioned – support for group savings, business training and help with building equity.

Once the process of sensitizing disabled people to self-employment has begun, programs can foster an understanding of money management through gradual exposure to financial services with higher complexity. One effective way to do this is

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7 Please also see cluster 3, access, Workshop 7, Poverty and indebtedness among people with disabilities: is microcredit an effective answer or cause of further debt?
through group saving and lending, with support from disabled people’s organizations to reduce the credit risk. A possible next step is to find microfinance institutions interested in including people with disabilities to expand their customer base. The new entrepreneurs can also be helped to develop their products and their penetration in local markets. Finally, commercial banks can be involved once businesses progress to an appropriate size.

To make such efforts sustainable, partnerships with disabled people’s organizations can help promote microfinance schemes, enhance their performance, monitoring and follow up, and consolidate lessons learned. Creating structures to replicate and scale up success is also important and this might involve partnerships between the various stakeholders. Above all, inclusion should be a goal of the program, both in terms of including people with disabilities in the economy and in their participation in mainstream financial institutions.

The Trickle Up program is one example of how inclusion can change organizational cultures to reach more people with disabilities. Since 1979 it has targeted the most vulnerable people who cannot access mainstream microfinance institutions or qualify for loans. By 2007, 7% of their clients were people with disabilities. The target for 2015 is 15% and they have worked with DPOs to help achieve this. They have also taken steps to become inclusive themselves, including changing the language they use (for example, using the phrase “differently abled”) and providing disability training to all of their staff.

In the workshop discussions, participants made the point that the people who may seem to be the poorest, such as newspaper vendors and beggars, may not be – the poorest people with disabilities may be invisible to outsiders and doing very little. Akin to this are the problems faced by everyone in the world’s poorest countries, such as poor transport infrastructure, which can be even more acute for people with disabilities.

They also pointed out that there are many ways to use groups for savings, including self-help and campaigning groups, groups for people with one type of disability, groups of people with different impairments and mixed groups of disabled and non-disabled people. Further investigation is needed to test which model is most effective.

Microfinance institutions’ attitudes sometimes cause problems, such as denying access to financial services to displaced people, which makes it harder for them to resume financial independence. As many such institutions have now turned into banks, they could adopt the kinds of diversity policies now in place in many of the banks.

The workshop called for a range of action points, to increase disabled people’s participation in the wide range of activities that could support them in entering the workforce:

1. Inclusion and mainstreaming, including training on how to become inclusive, are vital for all microfinance stakeholders working to enable people with disabilities to access financial services
2. Lobby governments to provide more inclusive policies for microfinance institutions to include and become accessible to people with disabilities. Anti-discrimination legislation should be enacted.

3. Address the lack of knowledge among banks and microfinance institutions about disability, as well as their fears that people with disabilities represent bigger business risks than other groups.

4. All stakeholders should make a commitment to considering potential market research opportunities. This is especially important within the disability sector as it can break stereotypes about jobs that people with disabilities can do.

5. Involve DPOs in developing the policies of microfinance institutions.

### 3.2.3 Making social protection a hand up — Workshop 3: the role of state safety nets in low income countries

Speakers: Kate Gooding, Sightsavers International, UK, and Thomas Ongolo, Secretariat of the African Decade, Kenya
Pradeep Kumar, former Disability Commissioner, Government of Karnataka, India

“In Europe, 14% of the OECD’s GDP is spent on social protection schemes, but less than 2% of Africa’s GDP is spent on social protection.”
Alessandro Conticini, Senior Chief of Adolescent Development, Protection and HIV/AIDS

Social protection as innovation and a tool to promote inclusion was an important theme for this workshop. There is increasing interest in social protection, in the form of service provision or financial support, for people in many different situations, and the question is how to make it most effective for people with disabilities.

When considering cash grants, speakers and participants called for them to be seen as a “hand up” rather than a “hand out.” Several studies of social protection have found that it can improve nutrition, health and access to education for recipients and their households. Also, contrary to assumptions that social assistance promotes dependence and discourages work, research has also found that cash transfers promote economic activity through investments in microenterprises and the maintenance of productive assets.

How to make social protection truly inclusive is at the heart of the issue, and there are good reasons to consider disabled people as a target group. For instance, there may be extra costs associated with living with disability, and state social transfers can compensate for these. There is also the acknowledged high level of poverty faced by many disabled people, which would automatically qualify them for social protection in
some countries. The question of access is always critical however, as institutional, social and environmental barriers may stop people from learning of suitable programs or prevent them from taking the necessary steps, such as travelling to government offices, to participate in them.

There is also debate about whether social protection transfers should be in cash or in kind, such as providing assistive devices. In-kind transfers sometimes have the benefit of bringing a specific support, for instance mobility aids, which allows people to participate more widely in their communities. Some devices may also be too expensive for people to afford without help, or unavailable locally, so in-kind support can help disabled people access the technology that is most appropriate for their particular needs.

The next question is about eligibility. Social protection programs in some countries extend to all people with disabilities, while others apply only to those in financial need. Even defining disability becomes an issue: is someone temporarily disabled eligible? Should the relative severity of impairment be considered? Should it apply only to those who cannot work and if so, how is this determined? DPOs can help clarify these issues with governments and monitor how well the programs are actually reaching the intended participants.

Another alternative is to link cash payments to school or health clinic attendance. While this can promote fuller participation, it can also exclude people with disabilities from benefit schemes if the schools or health services are not accessible. Alternatively, it could put pressure on services to become inclusive.

Overall, the workshop speakers and participants believed that it is important for cash transfers to be part of wider action to support inclusion and greater rights. Once again the question is how these measures are handled, and the participation of people with disabilities and disabled people’s organizations in their design and implementation, is very important. Issues to consider in assessing people’s support needs include their assets, income, costs, skills and other factors affecting employment – not just their impairments. Is there a role for programs that provide both services and cash, depending on need?

Many of these principles have already been put in place in South Africa, where South Africa Disabled People, a national disabled people’s organization, advocates for grants to be seen as part of the inclusion process and contributing to overall poverty reduction. People with disabilities were involved in developing South Africa’s cash transfer program, which pays Rand 940 to over 1.4 million people a month.

The grants are typically used to cover extra costs related to disability, such as use of more expensive transport (private or adapted) where public transport is inaccessible, attendant care services, assistive technology, rehabilitative equipment or devices, transportation services, housing and workplace modifications, interpreter or reader services, and periodic medical or hospital visits.
The funds may also be used to pay for education or health services, buy goods and food for the household and cover other living costs. While the size of the grant may not allow people with disabilities to live independently, it can allow recipients to contribute to household expenses and their families’ wellbeing in ways that were impossible before. This may both increase their status within the family and community, and enhance their participation in society.

The Indian state of Karnataka can tell a similar positive story. In 1995, the People with Disabilities Act provided for a quota of 3% of funds used in all poverty alleviation programs to be targeted towards people with disabilities. There is a strong civil society sector in Karnataka, and from the beginning, disabled people’s organizations and NGOs were involved in participatory governance of the program and associated services. Some of their joint achievements include:

1. The Office of the Commissioner for Disabilities built a strong coalition
2. Nodal NGOs were identified in all districts to focus on promoting disability rights, legislation, government schemes and poverty alleviation programs
3. Getting support in the media.

There was a District Disability Management Review, a tool for practicing participatory governance in disability, which they saw as having four phases:

1. Capacity building of the key stakeholders
The UK Department for International Development has named social protection as one of the “four essential public services,” alongside education, health, and water and sanitation.

Disabled people have an equal right to social protection, enshrined in the Universal Declaration of Human Rights, and reconfirmed in the UN Standard rules on the equalization of opportunities for persons with disabilities (Rule 8) and the UNCRPD (Article 28).

It was also felt to be necessary to educate stakeholders about the different quotas. To do this, the district nodal NGO organized awareness-raising workshops and provided information about programs, schemes and government targets to people with disabilities in various formats.

Involving disabled people in planning to this degree led to a “results based management program.” Monitoring and evaluation of how the quotas were implemented was undertaken by the district nodal NGO and other stakeholders, and held in the presence of four different authorities:

1. District-in-charge Minister
2. District in-charge Principal Secretary
3. Commissioner for Disabilities

This process includes information on the benefits transferred to people with disabilities in the district, and any shortfalls had to be explained.

The Office of the State Commissioner for Disabilities was a great help to this process, as an independent and autonomous office with quasi-judicial powers. It was the first state office to function as a “civil court,” and this model was recommended to other states and praised by DFID in its 2005 Country Report.

Karnataka’s dynamic process of implementing quotas for participation in social programs can teach several important lessons, believes Pradeep Kumar. It takes more than political aspirations to make quotas work: you need an administrative system that is sensitive to disability and a proactive civil society. Above all, this kind of participatory governance must be based on the principle “nothing about us, without us.”

To make the various forms of social protection work best for people with disabilities, workshop participants called on governments and civil society to:

1. Evaluate what social protection is needed
2. Involve disabled people in program design
3. Develop participatory governance
4. Include more support for children, including daycare and parenting, and family support services
5. Evaluations are needed to both advocate for programs and to make them more effective.
3.2.4 Poverty and disability programs must be integrated – Workshop 4: Poverty reduction strategies for the poorest of the poor

Speakers: Philippa Thomas, UK Government Department for International Development, Zimbabwe
Professor Nora Groce, Chair, Leonard Cheshire Disability and Inclusive Development Centre, UK

Programs to address poverty and disability are caught in a vicious circle, contends Philippa Thomas. First, there is growing international consensus about the aims and modalities for delivering poverty reduction. Disability is also an increasing concern among those working for poverty reduction and the promotion of human rights. Yet disability largely remains off the poverty reduction agenda. Why? The reasons behind this problem encompass many fields:

1. Disability stigma and ignorance
2. Different understandings and interpretations of the social model of disability
3. Insufficient appreciation of the relationship between poverty and disability.

All of these can result in mistrust between people involved in disability and poverty reduction, and render disability a special interest topic that may be difficult for those not directly involved in it to understand. A number of differences in approach can contribute to this mutual unintelligibility:

Data and statistics: Globally, existing statistics are insufficient and may not meet the different needs of mainstream development actors and people in the disability movement. People with disabilities may be unable to access data for a range of reasons, and the two sets of stakeholders may use mutually exclusive terminology and jargon. Beyond this, disabled people may be “invisible” to development organizations, and people with disabilities may not know of development activities.

Donor priorities: Donors now often focus on harmonized approaches to development, such as Poverty Reduction Budget Support (PRBS), when a donor provides funds directly to a partner government’s central exchequer, to support their programs in poverty reduction. Another increasingly used mechanism is a Sector Wide Approach (SWAp) process, in which donors give significant funding to a government’s comprehensive sector policy and expenditure program (for example on health or education), consistent with a sound macro-economic framework. There is a shift away from direct project support among donors, and less emphasis on support to civil society. Funding tends to be large in scale and many donors have limited expertise in disability.

Civil society organizations may be small scale: Organizations by and for disabled people, on the other hand, often focus on small-scale projects. They may have limited mainstream development expertise, and a small capacity to adapt to the new donor approach. Unfortunately, there may also be questions on how representative and accountable some of the civil society organizations really are.
In an ideal world, states, service providers and DPOs would work together. The state would define rights and entitlements through legislative and policy framework, set standards and monitor implementation. It would also provide resources and ensure that mainstream services, particularly health and education, are accessible to disabled people.

Disability service providers would help reduce the impact of impairments through access to assistive devices and rehabilitation, and enable disabled people to access their rights. The DPOs would advocate and lobby for disability rights, and ensure that the state and service providers remain responsive and accountable to the needs and rights of disabled people.

The DFID experience in Zimbabwe shows that this kind of cooperation is beginning to be possible, even in our far from ideal world. The situation for people with disabilities in Zimbabwe is a result of many contradictions. The country is experiencing a protracted humanitarian crisis: the causes may be contested but the effects are clear—hyperinflation, economic decline, rising food insecurity and deteriorating basic services. Disabled people are among the poorest and most marginalized in the country, and suffer disproportionately from Zimbabwe’s deterioration. They are more likely to need health care than non-disabled people, and are less able to collect water from alternative sources or spend hours in queues for basic goods. Disability support services have collapsed. A focus on short-term humanitarian assistance has further marginalized disability issues.\(^8\)

More positive developments include most NGOs and UN agencies’ use of disability as a targeting criterion to identify the poorest and most vulnerable households. A disability rights act was also passed in 1990, there is a disability advisor in the Office of the President and there are disability benefits and grants, although these have lost all value because of hyperinflation.

DFID now supplies humanitarian assistance to the Zimbabwean people, with a focus on saving lives and livelihoods and promoting universal access to HIV/AIDS prevention, treatment and care. Recently DFID commissioned a disability scoping study and selected disabled people as consultants. The study process was an empowering and transformative experience, challenging attitudes. Mainstreaming disability in its flagship livelihoods program, The Protracted Relief Programme (PRP), is DFID’s priority:

1. All concept notes and proposals for PRP must address disability
2. NGOs will be encouraged to partner with disabled people’s organizations
3. Local disability advisers will be appointed.

Disabled people’s organizations (DPOs) are being supported to participate in program meetings.

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\(^8\) For more information on the impact of humanitarian aid on disability, please see the section in this report on Discrimination Workshop 4: Discrimination in emergency situations: policy and practice.
DFID has also worked closely with the Foreign Office who supported a capacity building needs assessment of DPOs and a dialogue workshop, which ended with the two national umbrella DPOs signing a memorandum of understanding, to guide future cooperation.

DFID has also raised awareness of disability among other donors and this has led to UNICEF and the European Commission identifying disability as a priority issue. From their experiences, DFID has learned several lessons for further disability work in Zimbabwe and other countries, including the need to gather and disseminate evidence and analysis, to build coalitions of development and disability organizations, and to manage expectations. It is also important to accept that this process has no quick or easy answers, but offers the opportunity for everyone involved to embrace and promote change.

Professor Nora Groce then turned the workshop’s attention to the people with disabilities who may not be being included in current poverty reduction programs. Often, she contends, global poverty is discussed within a very narrow point of view, even within the disability realm. Much of the ongoing dialog is framed in terms of employment, while the majority of the developing world is self-employed, and many people combine a variety of income generating activities to support themselves and their families.

To be really effective, we therefore need to conceive and design programs that allow individuals with disabilities the autonomy to decide how and when they work, and whether they would prefer to work for themselves or for others. At the moment, poverty reduction programs often concentrate on teaching just one skill or a limited skill set to disabled persons, which puts them at the mercy of a single employer.

With this comes the need to support people with disabilities while they learn the skills to manage their own financial affairs. Too often, when disabled people get a job, their wages are not directly under their control: even if they are working, their ability to decide for themselves how and when to spend their money is significantly limited. This is particularly true for many disabled women in developing countries. (Certainly this is a wider concern for many women, but being a disabled woman will compound this issue.)

Even when people with disabilities are allowed to keep the money they earn, they often have little experience in understanding how best to budget and save this income. Often, parents and teachers spend little time teaching an understanding of finances and money to their disabled children, while the same subject is considered an important part of coming of age for non-disabled children in the same households or classrooms.

Additionally, job training and skill building is often framed as an adult concern, with education for children with disabilities focusing on school-based education that provides basic skills such as reading and math. Excluded from this scenario are the millions of children who do not get to school in the first place, or those who leave school early.
These children still need some sort of non-formal educational outreach to provide them with skills that will allow them to earn a living in later life. Obviously, the more education a disabled child can get, the better – however, practical consideration should be given to ensuring that children who cannot complete a basic education are not also unable to support themselves in future years.

Of even greater concern are the vast majority of disabled adolescents whose education has ended, but who are not being given the skills and job training to enter the adult world of work at the same pace, and at the same age, as their non-disabled peers. This leaves many disabled adolescents facing an enormous time gap, during which they wait at home and are bypassed by their non-disabled peers who begin to enter the workforce. Instead of being included in the workforce in an age-appropriate way within their cultures, their entrance to the workforce is delayed, and thus their experiences become markedly different from those of their non-disabled peers.

Disabled adolescents are also often put at a significant disadvantage from the outset, because even if they are fortunate enough to get an education through the schools, they are often left out of internships, apprenticeships and part-time after school jobs that help young people build skills they will need for the workforce. Additionally, even when a disabled adolescent is able to get an internship or first job, there is little room for failure. Should they not perform well in the first job opportunity they have, family and community members are often quick to decide that these young people should not be in the workforce or are unemployable.

In fact, many adolescents – in both developed and developing countries – do not thrive in their first job (as many readers will recall from their own experiences as adolescents with their first jobs), and poverty reduction programs must make sure that disabled young people have the same right to try, fail and try something else, as all other young people.

The Leonard Cheshire Disability and Inclusive Development Center will be investigating issues of self-employment in developing world economies in a series of research projects over the next few years.

Workshop participants then went on to call for three action points to tackle the interconnected fields of disability and poverty reduction:

1. Identify methods and approaches that reach and engage persons with disabilities who are currently not involved (poorest of the poor)
2. Develop strategies to ensure that awareness of persons with disabilities who are the poorest of the poor is raised
3. Identify where we can leverage opportunities to build capacity in multiple stakeholders.
3.2.5 Inclusion is an economic necessity — Workshop 5: Mainstreaming disability in employment

Speakers: Imtiaz Mohammed, Senior Programme Manager for Asia, Leonard Cheshire Disability, UK
Mr. Chi Junchang, International Department, China Disabled People’s Federation, People’s Republic of China

Is mainstreaming what we need and want? Imtiaz Mohammed opened this workshop by asking participants to consider what is really most effective in supporting people with disabilities into work. While we may celebrate the fact that many NGOs, including Save the Children and World Vision, and bilateral donors including DFID and USAID, have integrated disability into their programs, we also recognize that sometimes disability needs to be addressed as a specific issue.

This is referred to as a twin-track approach and might include, for example in the health sector, first promoting general health care services and ensuring that they are accessible to people with disabilities. The other part of the process is to provide disability equality training for service providers, adapt facilities and provide health information in accessible formats. It could also extend towards sensitizing providers to any special health care needs that people might have because of their disabilities.

When the twin-track approach is applied to employment, it is important to ensure that government legislation and policies target all vulnerable groups, including people with disabilities, and that a distinct business case is made for disabled people’s economic empowerment. For instance, if the up to 10% of the population now excluded from work because of their disability could be employed, this would have a significant impact on the overall economy. In order for this to happen, some adaptations to employment conditions may be necessary. This could include making allowances for increased travel time or increasing access to workplaces.

The corporate sector can be cynical, but it can be useful for people with disabilities simply to be exposed to the world of work. Disabled people in workplaces will be advocates for disability among others with whom they work. One approach to increasing the participation of people with disabilities in work is to have a champion at work, maybe one person on every floor or department who advocates with disabled colleagues for their needs to be addressed.

Many work initiatives for people with disabilities focus on small-scale employment, yet it is debatable whether this kind of work truly lifts people out of poverty. Entrepreneurs may be born, not made, and while building their skills is important, some people will be more comfortable and productive in other kinds of work. Social protection programs must also address people’s particular needs and be structured to help people overcome barriers, rather than enforcing them. Some specific actions to promote employment include:

1. Advocacy/campaigning on the “disability business case”
2. Provision of appropriate training and support
3. Flexible forms of employment
4. Apprenticeships/placements
5. Assistance at work and personalized support
6. Adaptation of premises and equipment
7. Promotion of entrepreneurship programs
8. Meeting the complex needs of people with severe and multiple disabilities.

Mr. Chi Junchang of the China Disabled People’s Federation echoed Mr. Mohammed’s emphasis on the inclusion of people with disabilities as an economic necessity. In China, 40 to 60% of disabled people are not employed, and those who do work earn less than half the amount of non-disabled people.

Although a law in China mandates that 1.5% of employees in every business must be people with disabilities, many employers would rather pay a fine than hire disabled staff. Because of lower levels of education, disabled people may also lack some of the skills needed for employment. The CDPF has explored three ways to overcome these problems:

1. Collectively assigned employment
2. Employment in normal workplaces
3. Entrepreneurship, a new area for people with disabilities because of previous programs that trained disabled people only in specific skill areas.

Entrepreneurship is often the best way for people with disabilities to get to the highest level of employment that they can attain. To support this process, the CDPF advocates strengthening government policies, raising people’s educational levels, business management training, funding, and technical support for the young businesses.

Using successful ideas from other countries, the CDPF started a program in Wuhan, a province of 8.5 million people. Using a course originally created by the government for people who had been laid off their jobs, “Start or Improve Your Own Business,” the CDPF targeted people with disabilities with new training methods. These included increasing students’ confidence and enthusiasm about starting their own businesses and simulating businesses in classrooms. Out of 105 participants, 21 started their own businesses, which range from computer repair to massage. Nine students who needed seed capital to get started were given loans of up to $1,500. Most of the businesses have been successful and some new entrepreneurs now employ other people, thereby contributing even more to the economy as a whole.

Workshop participants also shared their experiences of employment promotion. Javid Abidi from India pointed out that access is fundamental to mainstreaming. For instance, in India, some employers are willing to hire people with disabilities, but their buildings are not accessible. Access also extends beyond buildings, other participants added. For instance, UNECA employed a deaf staff member in their Department of Statistics, but did not provide an interpreter, which made the job significantly more difficult. Beyond

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9 Please see Javid Abidi’s panel speech on countering discrimination in the social sector, in the Discrimination cluster of this conference report.
this, access to computers might mean that disabled people could work from home and cut down on travel difficulties.

It is also important to consider how social protection and rights interact. For example in Uganda, a disabled man got a job in a computer department, but was fired after a week because the employer said that he could not lift the computers. Is this really a requisite skill or is it an excuse?

Some participants were also concerned that creating entrepreneurs might not meet market needs and that it might not be mainstreaming. Mr. Chi believed that in China, however, the entrepreneurs did meet market needs, because they based their businesses on what they believed would make a profit. Other people added that in smaller or less developed economies, entrepreneurship might be more important as a way into work.

When the UNCRPD is ratified and implemented, mainstreaming will not be a matter of choice. To help with this process, participants thought that employers should be given incentives to include people with disabilities, and labor laws must change. Training is essential, but participants echoed the representative from Barclays Bank, who believed that training should only be given if there is a good chance that it will lead to a job. The Convention implies sharing of responsibility – employers will not be motivated to employ people with disabilities unless there is something in it for them. To elaborate on this, participants added that some people with disabilities have been living so far outside the world of work that they do not work well, and need training to understand the mindset and requirements of being employed.

Together, the workshop participants called on employers, people with disabilities and governments to recognize:

1. Making a business case for the inclusion of people with disabilities in the workforce should include focusing on what disabled people can offer
2. Financial incentives are a good idea in the area of access, and the costs can be offset against taxes
3. Use new technology and new ways of working to make it easier for people with disabilities to take part in paid employment
4. Entrepreneurship and paid employment are appropriate in different areas, situations and countries. People must take the overall economic situation into account when deciding which method of training or work promotion is appropriate.

10 For more discussion of the role of entrepreneurship and disability, please see sections in this conference proceedings on Poverty, Workshop 2, “Microfinance is not the tool to reach the poorest of the poor” and Access, Workshop 7, “Poverty and indebtedness among people with disabilities: is microcredit an effective answer or cause of further debt?”

- In China, an average income for a person with a disability is US$635 while the average income for a non-disabled person is US$1,572.
- We can’t measure what qualities people with disabilities can bring to society through their participation in the labor market: a holistic approach to disability means that economics need not be the only criteria for inclusion.
Poverty and disability are linked, claims Jean-Francois Trani, but it is poverty of opportunity and not necessarily a lack of money or assets that is the important factor. Two independent studies of the relationship between poverty and disability in two very different countries – Afghanistan and Zambia – provide the evidence for this possibly contentious statement.

The research in Afghanistan, a country that has been in conflict for over two decades, surveyed 5,130 households in 34 provinces comprising 38,320 individuals, and identified 1,038 people with disabilities. In Zambia, which is not a post-conflict country, the survey included 5,751 households with a total of 28,189 people from nine provinces, and 3,090 people with disabilities were found.

Using the International Classification of Functioning (ICF) developed by the World Health Organization, questionnaires in both surveys covered health, education, income, activity, debt, livelihoods, self-perception, awareness, marriage and social participation. All the participants were from 14 to 65 years old and the disabilities surveyed included mobility and sensory, intellectual and learning, behavioral and psychological, communication and social functioning limitations and fits, seizures and epilepsy.

The results in both countries were similar: age, as opposed to poverty, was the strongest determinant of disability prevalence. The second strongest association was a not having an education, and people who had gone to primary, secondary or tertiary education had a lower rate of disability. Perhaps not surprisingly, a higher proportion of unemployed people are at risk of disability than employed people. This might show a link between economic poverty and disability, but does not indicate which came first.

In Afghanistan, use of public health facilities was associated with a higher rate of disability, but, conversely, perception of availability of public health facilities was associated with lower risk of disability. Overall, the gap between rich and poor, as measured by their own statements of their assets, was not a significant factor in disability prevalence.

Certain other patterns and differences between the two countries were evident, however. In Afghanistan, women are more at risk of cognitive, mental or multiple types of disability, including epilepsy, but this is not the case in Zambia. An increasing risk of sensory impairment is associated with single or engaged respondents compared with married respondents in both countries. This is also true in Zambia for mobility and cognitive, mental or multiple impairments. In Afghanistan, respondents belonging to
the middle wealth group are relatively more at risk of mental impairment, but not any other type of disability. This is not the case in Zambia, where a higher rate of sensory impairment is associated with being among the wealthiest group. Living in an urban area is correlated to a high rate of sensory impairment in Afghanistan, but not in Zambia.

It is widely believed that discrimination, lack of access and exclusion – all-important themes at the conference – make people less able to reach existing resources and more at risk of multidimensional poverty. It is this multidimensional poverty that is linked to disability, this research suggests. Poverty is a great leveler or equalizer, and affects families with non-disabled family members to the same degree as it does families with a disabled family member. Yet these results show that poverty measured by level of assets is neither systematically associated with disability measured by types of activity limitation, nor can it be considered as a determinant factor of disability.

Perhaps the word deprivation is a more appropriate description of the set of socioeconomic factors that have an impact on poverty prevalence. For instance, disabled people are less likely to be educated, employed and have adequate access to health care in both Afghanistan and Zambia. Therefore the presenters call for an integrated approach to tackle the needs of disabled people and incorporate them into the mainstream of multidimensional poverty reduction strategies.

It is also important to acknowledge that disability is not a permanent state that remains unchanged throughout life once acquired. It is a matter of definition, of perception and of various environmental, social and political factors that are different in different contexts. In the future, as our understanding, awareness and knowledge of disability increases, the prevalence of disability will increase – to include those with mild or moderate impairments and those who have lesser yet genuine needs. At the same time, an opposing process will result from better access to health services, nutrition and hygiene in low income countries such as Afghanistan and Zambia, meaning that fewer people will face the consequences of preventable illnesses that are the cause of several disabling conditions. So, as disability itself changes, our understanding of its causes and affects will need to change along with it.

One means that people with disabilities have found to challenge multidimensional poverty was discussed by Teddy Kaberuka from the National Federation of Persons with Disabilities in Rwanda. During Rwanda’s emergency period, defined in this context as lasting from 1994 to 2000, there was little data available on disability and no programs to address it. Since then, disabled people’s organizations and disability activists have been reshaping their link with government structures, and have formed the umbrella organization that Mr. Kaberuka represents.

After 2005, the disability movement in the country strengthened itself through improved communication. Government welfare provision has improved, but people with sensory impairments remain excluded from many interventions. Because of the seriousness of the conflict in Rwanda, people might have expected that tensions would still exist
between the different ethnic groups, but this has not been a problem within the disability movement, Mr. Kaberuka reported. World Bank funding has supported programs for demobilized former combatants, but these groups have managed to work within the national organization.

The long period of conflict and other causes of poverty within Rwanda have presented other constraints, however. The topography of the country can make travel difficult and there is a lack of infrastructure in many areas. There is also insufficient data and information for use in lobbying, and people with disabilities can still be stigmatized within the wider society. A national census to identify disability prevalence would be very helpful.

Disabled people’s organizations also often struggle financially and Mr. Kaberuka calls for international NGOs and multilateral organizations such as the UN, to strengthen and empower them. The process, known as LLRD – Linking Relief, Rehabilitation and Development – would also help ensure that disability is integrated into the development process.

Following these thought-provoking presentations and a lively discussion, the workshop participants came up with the following calls for action:

1. Include disability data in national censuses
2. People with all “types” of disabilities, including those wounded by war and others, should be represented
3. Strengthen disabled people’s organizations in conflict-affected countries and raise awareness of UN structures
4. Distribute resources more effectively
5. More detailed analysis of multidimensional aspects of poverty – especially the link between poverty and disability – should examine specific factors that impact on disability. These might include marriage, access to health care, decision-making processes, etc.

Our results show that poverty measured by level of assets is neither systematically associated with disability measured by types of activity limitation, nor can it be considered as a determinant factor of disability. – Jean-Francois Trani.
**3.2.7 Collective power empowers individuals — Workshop 7:**
**Self-help groups and empowerment**

Speakers: Peter Coleridge, Consultant, UK
Laurence Hee, National Council of Cheshire Homes, Malaysia

“But mainstream free-market theory suffers from a ‘conceptualization failure’, a failure to capture the essence of what it is to be human . . . . [This view], to quote Oscar Wilde, knows the price of everything and the value of nothing.”

Muhammed Yunus, Founder, Grameen Bank

Self-help groups have the capacity to empower people to overcome not just economic poverty, but also the poverty of opportunity caused by lack of access and limited participation in society. Poverty, contends Peter Coleridge, is not simply a scarcity of resources; it is a denial of the fundamental freedom and opportunity to develop as a human being.

In helping to create a society in which all citizens have equal opportunities to develop their full potential, self-help groups have a role in facilitating people with disabilities to gain increased confidence and self-esteem. They can also create economic opportunities and foster efforts to achieve full human rights.

In India most groups started as issue-based and 90% of members were women. Most have now become mainly savings and credit groups that act as an alternative to moneylenders and offer the opportunity for people to save together. The savings form a pool of capital, from which loans are given to members to start or improve their small businesses, or for other reasons. This approach is in contrast to some other microfinance programs, such as the Grameen Bank, which uses outside money for loans and does not require prior savings.

Seeing the success of the more than seven million self-help groups in India, which now reach approximately 140 million people, large institutions such as the World Bank and the government now support them as tools for poverty reduction. While this is a positive development overall, it runs the risk of seeing self-help groups as focused mainly on material gain, and could ignore the human process of group interaction. It might also make the groups open to political manipulation.

Using self-help groups specifically for people with disabilities began in the mid-1980s. Originally based around disability as an issue, they have now followed most of the other groups into savings and credit. Forming federations has given groups a voice at district level that encourages politicians to view the disabled members as an organized constituency.

Some of the key principles involved in starting a group are that they require skilled and thoughtful facilitation and that no two groups are the same. The first meetings aim to
build confidence, not solve problems: listening to other members and discussing issues need practice, particularly considering the diversity of disabilities, education and economic background of some participants.

Successful groups will usually develop a mission and initially focus on something easily achievable, such as statutory rights. Some common features mark them: clear goals, consistent membership, active participation by all and a focus on their own issues, ideas and feelings. As such groups develop, they often share responsibilities, resolve conflicts constructively and agree and keep to procedures. They can then join other groups and other movements working towards the reduction of poverty and deprivation.

Issues for groups to consider include who owns them – do they belong to NGOs or are they independent? Lobbying for entitlements will only work if those entitlements exist, so wider campaigning may be necessary. The fact that members have disabilities themselves does not mean that they have complete knowledge of rehabilitation, and other services in their areas and people with communication impairments may be excluded, or find it difficult to contribute.

The workshop went on to discuss whether mixed groups of disabled and non-disabled people would be effective. People generally thought that they could work, but if people with disabilities became a minority, it might be difficult to discuss issues that relate specifically to their needs. The same is true for women entering men’s groups or mixed groups that have a gender imbalance – some people could feel outnumbered.

Including people with learning disabilities is also a challenge, as is working most effectively with facilitators. While using a facilitator is an essential part of the process, people need to be aware of potential problems – for example, workshop participants shared how sometimes facilitators take too much ownership of groups and do not leave at an appropriate time. Another issue is illiteracy, which can prevent people from accessing services or participating as fully as other members.

Laurence Hee then discussed how disability work in Malaysia is shifting from a charity perspective to a rights-based approach that is about empowerment. Malaysia benefits from a government that is committed to supporting people with disabilities and has
introduced several programs since 1990 to strengthen employment opportunities. Through these schemes 7,013 disabled people have been successfully placed into jobs, and a new program introduced in 2007 has already supported 64 people to establish their own businesses, including mobile phone repair shops, photocopying outlets and cyber cafés.

Lower paid workers with disabilities can also receive grants from the government to cover the difference between the wage they earn and the amount they need to attain a basic minimum standard of living. The government and the National Council of Cheshire Homes Malaysia both also offer training in independent living and appropriate support to meet individual needs, with an emphasis on building independent decision making skills. For people whose disabilities might make it difficult for them to compete on the open market, the government also supports sheltered workshops that include a training component. The goal is for the training to help people get to the point when they have enough skills to work in the mainstream economy.

A number of NGOs in Malaysia focus on disability, among them the Cheshire Homes, which have recently shifted from a focus purely on residential care to an empowerment model that includes inclusive education, livelihood support and advocacy and campaigning. In the Selangor Cheshire Home, a skills training program prepares people with disabilities for waged employment and starting their own businesses. They have focused particularly on people with learning disabilities, who have taken courses in baking, office work, hospitality, and information technology. When they finish the courses, people are helped into work through additional training in business management and assistance in obtaining small loans for seed capital.

Among disabled people’s organizations in Malaysia, the Beautiful Gate Foundation program in economic empowerment stands out for being fully managed by and for people with disabilities. They have set up four centers in different locations, covering people with different needs in rehabilitation and employment skills. Their diverse programs include peer counseling, transport, job referral services and support for financial needs, self-employment and assistive devices. Training extends to courses in leadership skills, bookkeeping and advanced computer use, promoting the idea that the widest possible range of careers is open to people with disabilities, including senior management roles.

- There are now over seven million self-help groups in India reaching approximately 140 million people.
- Government training courses in Malaysia for people with disabilities have included such non-traditional subjects as fashion design, multimedia and fine arts.

Workshop participants then called for a number of specific steps to promote empowerment:

1. Advocate for multifaceted economic empowerment programs to address different abilities and move away from the traditional model
2. Share more experiences to facilitate this process
3. Mainstream disability in poverty reduction strategies
4. Take an integrated approach to sheltered workshops to make them more holistic, identify useful markets/outlets and then share this information. Sheltered employment may eventually convert to open employment to ensure integration.

3.2.8 Fighting marginalization through engagement—Workshop 8: Community development

Speakers: Tingyu Wang, Regional Programme Manager for East Asia, Leonard Cheshire Disability, Thailand
Maurice Kilduff, Executive Director, Cheshire Homes South Africa

“Despite recent achievements, people with disabilities remain the single largest sector of the least-served and most discriminated against in almost all societies in the Asia Pacific region.”

United Nations Economic and Social Commission for Asia and the Pacific, 2003

Reducing poverty and achieving full human rights: without one, you can't have the other. So concluded the participants in this workshop, who believe that for people with disabilities, marginalization is at the heart of both of these issues.

Community development in this context should be a rights-based and inclusive process. Since previous UN treaties and conventions already gave rights to disabled people (as they did to all people), the purpose of the UNCRPD should be to realize these rights, believes Tingyu Wang. To be successful, programs need to address a holistic range of issues, including economic empowerment, livelihood development, inclusive education, and advocacy and campaigning. They also need to facilitate change among a number of different stakeholders, including employers, families, government agencies, community groups, NGOs and international donors. Self-help groups can play an important role in interacting with all of these other types of organization.11

Cheshire services in East Asia and South Africa have both taken this approach. For instance, in China, the first year of an economic empowerment program has had remarkable results, by building on a partnership among the China Disabled Peoples Federation, the Ministry of Labor and Social Security, and the International Labour Organization. Before taking this integrated approach, the small business training and development course had produced 17 disabled entrepreneurs in nine years. Yet after the partnership was established, it produced 12 new entrepreneurs in one year.

The project is successful because it addresses all the issues an entrepreneur will face, and works with partners to provide a range of services that include:

1. Small loans and training to start and run small businesses

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11 For more information on the role of self-help groups in community development, please see poverty workshop 7 in this conference report.
2. Vocational training and apprenticeships
3. Work with employers to make workplaces more accessible
4. Promoting the employment rights of people with disabilities
5. Improving social safety nets
6. Helping people access their government’s support programs.

Taking steps in just one of these areas, such as training, would not encourage the kind of institutional change needed. A similar process has taken place in Malaysia, where a livelihoods program works with both the public and private sectors to support employment opportunities for people. Taking on the wider human rights agenda, it also promotes acceptance of disability within workplaces. To date, 58 people have taken part in the program, which has focused on capacity building, social security and sustainable livelihood programs. Similar projects will soon be established in other East Asian countries.

In South Africa, where food has recently become very expensive, impoverished communities surround all 16 Cheshire services. To extend their work with people with disabilities, the Cheshire services have also started supporting disabled people’s families and neighbors in the wider community. Specifically, their objectives are to enhance:

1. Education of children
2. Skills transfer to the community
3. Economic empowerment of parents/guardians
4. Re-unification of the family.

As a first step, Cheshire Homes South Africa has established eight vegetable gardens adjoining Cheshire residential facilities. Being community based, they provide viable support to local people, and employment for Cheshire service users. There are also six hydroponics tunnels that grow a wider range of vegetables, and a commercial vegetable project that generates income for 38 families from a very poor area.

These are small beginnings for community development, but may offer a useful model, since vegetable gardening is not expensive and brings immediate, tangible benefits. It is also widely supported by donors, governments, volunteers and even some retail shops.

Working in the context of sustainable development, over time Cheshire Homes will become less involved in the management of community programs, which will become self-governing. In the short term, an international organization with Leonard Cheshire Disability’s reputation and resources can act as a catalyst to engage poor people with disabilities and those around them to access government funding and other social service and development programs.

Leonard Cheshire Disability and the Cheshire Homes can also play a role in convincing parents and guardians that education is of value. When unemployment is as high as 80% in some communities, this is a major task. For generations, the people around them, whether disabled or not, have experienced marginalization, with lack of access to employment even if they have managed to access education.
Under these circumstances, the delivery of immediate economic benefit to the community is the most convincing incentive. Without meaningful change in living standards, free education is not a great benefit. Schoolbooks, stationery, transport, clothing and nutrition remain insurmountable barriers. Community-based development from a rights-based perspective is probably as difficult a task as any individual or organization can choose to address, said Maurice Kilduff. To make it work, it must be multifaceted, and partnership is of the utmost importance.

To make this community development approach work best for people with disabilities, workshop participants reinforced the following points:

1. There is a need to develop and implement programs addressing the needs of marginalized people with disabilities, such as deaf blind people, people with intellectual disabilities, etc.
2. Institutions should be empowered to be in a position to build a database of parents and guardians of people with disabilities, who are staying or receiving services from Cheshire Homes, and make sure that service users do not lose contact with them.
3. Lobby government to develop early intervention programs in disability, and mainstream early childhood programs for children with disabilities.
4. Leonard Cheshire Disability should make sure that people with disabilities are consulted and included in any decision-making process within the organization that would lead to any change (positive or negative), and further make sure that representation is at all levels.

3.2.9 Reform in one sector does not create employment — Workshop 9: Reducing poverty through preparation in the labor market
Speakers: David Rojas, Organization of American States, USA
Flavio Coutoe Silva de Oliveira, Government of State of Minas Gerais, Brazil

Regional and continental initiatives need to understand local behavior through local partners. These elements become key to helping people with disabilities enter the labor market, sharing outside solutions, but adapting them to local needs and capabilities. Workshop speaker David Rojas based this conclusion on the experience of POETA – Partnership in Opportunities for Employment through Technology in the Americas, which provides employment training for people with disabilities. Created by the Trust for the Americas, an independent non-profit organization affiliated to the Organization of American States, POETA provides on-site training and support in the use of information technology at 69 sites in 18 countries, each training an average of 100 people with disabilities per year. Key project partners include the private sector, governments and civil society, which work together to create long-term, lasting employment opportunities for people with disabilities, and their communities.
The POETA program deals with both of what they call the “supply” and “demand” sides of employment. To meet the “demand” side, people with disabilities start learning to use computer hardware and software through project partners, including universities, schools and NGOs. In this way, project participants gain skills that are in demand by local employers.

POETA increases the “supply” of jobs that employers can make available to the trainees, by helping to create job placement opportunities, and by raising private companies’ awareness of disabilities and the benefit of having an inclusive corporate environment. They then follow this up by working with the media and fighting for disability rights using international legal instruments.

Realizing that teaching IT skills alone is not enough, POETA trains students to be prepared for the full range of experiences they will meet in the workplace. These additional disciplines include: social interaction; customer relations; conflict resolution; leadership; teamwork; self-esteem; time management; how to keep a job; and entrepreneurial skills for people interested in self-employment or running their own businesses.

Facilitating cooperation between the private sector and governments is another important feature of the POETA program. They have a strategic alliance with Microsoft and have reached out to work with the International Labour Organization to help include disability in international efforts to promote inclusion.

The workshop’s second speaker, Dr Flavio Oliveira, added to Mr. Rojas’s contribution with comments about employment of people with disabilities from the point of view of the government of the state of Minas Gerais, in Brazil. Dr Oliveira runs CAADE, an acronym for “Special Coordination of Support and Assistance to Persons with Disabilities,” which is part of Minas Gerais’s State Bureau of Social Development (SEDESE). CAADE supports, mentors and evaluates public policies for disabled people in Minas Gerais, and one of its programs is to provide a home to the only agency within Brazil’s national employment system dedicated to persons with disabilities.

State employment and income policies for persons with disabilities in Brazil are implemented mostly through the National System of Employment – SINE. In Minas Gerais there are 100 SINE service agencies that address employment needs for the population in general, including persons with disabilities.

In Brazil, people with disabilities have historically had a low level of education and professional qualifications. Access remains a problem, and both people with disabilities and employers tend to lack knowledge about disability and inclusion. According to data from the João Pinheiro Foundation, the population of the state of Minas Gerais will be 20.5 million by 2010. Disabled people represent 14.9% of the population, or up to 2,667,709 people, of whom 1,635,344 are between 15 and 59 years old and of working age.
On the positive side, companies in Brazil with 100 or more employees are required to employ people with disabilities as a minimum of 2% of their workforce. This figure rises to 5% for companies of 1,000 employees or more, and companies that do not comply are fined. To help companies meet the quota, the Brazilian government and the government of the state of Minas Gerais support training of disabled people, and run programs that raise awareness of diversity in the workplace.

CAADE’s goal is improvement of employment opportunities for people with disabilities. To make this happen, CAADE has partnered with the country’s biggest professional education agencies and universities to offer support and counseling to job hunters with disabilities. They also work jointly to promote cooperation among the social security and labor inspection bodies that enforce the employment quota system.

Workshop participants then discussed whether it is better to focus on the formal or informal sector to promote employment for people with disabilities. Their conclusion is that interested parties need to focus on both, but use different strategies for each. Government support and training programs can tailor their advice to disabled people, depending on which sector they hope to enter. In Brazil, this response may be tempered by the fact that the official policy is to improve inclusion of people with disabilities in workplaces, thereby increasing the social responsibility of employers in the formal sector. The Brazilian government also hopes to create a model of affirmative action that can be followed by other countries.

Inclusion may be seen as a horizontal process, meaning that it is necessary to work with schools and other teaching institutions, transport bodies and other sectors to promote true access to work. Laws alone cannot make it possible: rather, it is increased awareness that makes people embrace the principles behind the laws.

From this, workshop participants came up with six calls for action and guiding principles:

1. People with disabilities getting jobs is not enough; a comprehensive program of awareness raising, training and advice is necessary
2. A human resources plan is needed
3. Governments should be lobbied to create a board for employment of people with disabilities
4. The public sector must place people with disabilities in ministries responsible for social security and welfare
5. Recognise the importance of mentoring, supporting and counseling services for people with disabilities
6. A public board should be created to enforce labor laws and policies on employment of people with disabilities.

Although there are nine million people with disabilities in Brazil old enough to work, only 1.5 million are actually working. Of these, only 350,000 are formally employed and protected by labor laws.
In rural Bangladesh, becoming disabled later in life leads directly to poverty, according to recent research carried out in the Chuadanga region by Dermot Foley and Jahan Chowdhury. Located in the Khulna Division of the country, Chuadanga district is 300km southwest of the capital city Dhaka and had a population of 1,007,130 people in 2006. A baseline study by the Bangladeshi organization Impact Foundation Bangladesh found a disability prevalence rate of 5.7%. Of the 256 households they found with one or more members labeled as having a disability, 61% had less than 0.2 hectares of land, compared to over 60% of their peers who had more than one hectare.

Overall, Chuadanga is characterized by low income, a lack of fiscal resources and a general lack of support from non-governmental organizations and government agencies. It also has the lowest female employment rate in Bangladesh, and agriculture is the largest employment sector by far at 64%, with business a distant second at 14%. While Bangladesh as a whole experienced an increase in per capita income and living standards in the 1990s, the income gap between the highest and lowest earners in the country increased during the same period, and this is evident in Chuadanga.

The study selected 40 households that included people who had become disabled since 1997 and lived in chronic poverty. Four types of disability were included in equal amounts: blindness, orthopedic impairments, hearing impairments and mental disorders. To provide for a comparative analysis of the current socioeconomic structure, 32 households without a disabled member were also selected.

Their findings were striking: 87% of the participants who are labeled as having a disability left full-time employment within the first year after diagnosis. For participants labeled as having a disability for five years or longer, the employment rate fell from 13% in year one to 2% in year seven.

Participants who had not worked as laborers fared far better in terms of staying employed after onset of disability. For instance, 78% of the shop owners remained employed, compared to none of the people in manual or unskilled jobs, such as rickshaw drivers.

The wives of men who became disabled also ended up working fewer hours. Of the 90% of wives who noted an increase in the time required to care for their husbands after the onset of disability, 26% gave up 15 hours of work and 28% did 26 hours less of paid work per week than before the onset. Gender issues are also evident in the fact that treatment expenditure for women with disabilities consistently decline after women reach the age of 44, irrespective of household status. Medical expenditure is highest for males aged 35–44, but the difference between average expenditure of

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12 Bangladesh Bureau of Statistics, 2006
the remaining age groups is not statistically significant. The result of these factors on household income is devastating; beyond the psychological issues, they can lead to the loss of two incomes and an increase in expenses.

In terms of income, study participants with ambulatory disabilities were three times more likely to remain economically active than those with visual impairments. Among households without disabled members, the studies noted that 80% gradually moved up the social and economic ladder because of the uninterrupted employment spans (of both male and female earners) and relatively lower medical expenditure.

Some of the problems experienced by the households that include disabled people may result from the lack of state social services in Bangladesh, which leads people to seek help through social networks. These networks provide crucial emotional and practical support, and facilitate access to those formal services that do exist. The absence or decline of social connections that can result from the onset of disability makes it far more difficult to break away from poverty and ill health.13

In addition to this, the outcome of the onset of disability is rapid depletion of assets, increased financial and social burdens on the family, isolation from the community, increased debt, and impoverishment. In the study, the direct cost of treatment and equipment among affected families varied from five days to one year’s worth of normal income, with the average being four months’ worth.

Microfinance has become a significant stimulator of employment in Bangladesh, with more than 1,000 microfinance organizations opening since 1990, offering interest rates from 10% to 30%.14 The microcredit programs in Chua danga offered by organizations such as Bangladesh Rural Advancement Committee and Grameen Bank, stress their preference for women borrowers to foster their empowerment and self-sufficiency. Working on a peer-group basis, defaulting on loans by any member is the responsibility of the entire group.

Sadly, disability seems to have presented barriers to inclusion in such microfinance programs. Of the study participants, 8% of women with disabilities are members of credit-providing non-governmental organizations, as compared with 90% of non-disabled women. Even the mothers and wives of people with disabilities often find themselves excluded from such lending groups, as they are perceived as “high risk payers,” implying that there is a higher probability of non-repayment among those labeled as being associated with disability. This is consistent with the findings of Lewis and Sygall (1997) in their study in Tanzania and Malawi.15

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15 Lewis, Cindy and Sygall, Susan (eds.) (1997) Loud, Proud and Passionate; Including Women with Disabilities in International Development Programmes, Washington: Mobility International USA.
These findings lead to the conclusion that economic opportunities in Bangladesh are increasing, but access to them is now limited to people without disabilities and, in some cases, without family members with disabilities. Their predicament is greater than their perceived disabilities, because it also involves stigma and ignorance manifested in discrimination.

One step towards overcoming this lies in changing the practice of microfinance organizations to ensure that they genuinely include people with disabilities.

For people both with and without disabilities, the move from the farm to non-farm sectors of employment is impossible unless they learn the skills needed to participate in new forms of work, and take advantage of new economic opportunities. There may be many ways to facilitate this, but all, Mr. Foley concluded, have to consider how the context of discrimination against people with disabilities and their families negates broad-based poverty reduction programs.

To complement this assertion, workshop participants brought up the twin-track approach: broad-based development programs integrate disability into their work, and disability is also addressed as a specific issue. Government inclusion policies are also relevant because they could go some way towards fighting overt discrimination. Mainstream poverty alleviation programs could also include elements focused specifically on women and girls that would also address the needs of disabled participants or people with disabled family members.

To help bring these suggestions to life, workshop participants called on people involved in this field to:

1. Consider promoting revolving loans that focus on small units (families with members that have disabilities), mentorship opportunities and financial training to combat social isolation and increase ownership
2. Integrate protection of the family members of disabled children to access funds and training (which pertains to Article 27 of the UNCRPD)
3. Skills provided to disabled people and their families should be specific to their own communities and relevant based on local knowledge and input. This includes training for trades identified as locally feasible and viable.

To learn more about the role of discrimination in employment for people with disabilities, please refer to poverty workshop 5 in this conference report.
3.2.11 Older disabled people: a distinct social group — Workshop 11: Disability and aging

Speakers: Lizzie Nkosi, Country Programme Director, HelpAge International, Ethiopia
Hassan Musa Yousif, Ph.D., UNECA African Centre for Gender and Social Development, Human and Social Development Section, Ethiopia

The percentage of older people among Africa’s population is growing quickly. While there were 31.6 million older people in Africa in 1990, this will more than double to 64.5 million in 2015, the year for achieving the Millennium Development Goals.

The aging of the African population will have a significant impact on the number of disabled people on the continent. For instance, the 2001 population and housing census in Botswana indicates very clearly that disability rates increase with age, particularly among people aged 60 or over. The rate continues to rise as people get older: while people between 60 and 70 have a 10% disability rate, people over 75 have a 31% disability rate. Disability prevalence is also higher among older women, because they tend to live longer than men.

Poverty impacts on the rate of disability as well. For example, a person may have an impairment such as deteriorating vision, but if the right eyeglasses are available, the person will not be disabled. When people live in very poor or remote circumstances, however, a condition that could be easily treated elsewhere can lead to severe disability. Older people in Africa are more likely to have such conditions than other people, which is part of the reason that disability prevalence rises with age.

Since the incidence of disability goes up as people get older for many reasons including illness, the impact of chronic poverty and injuries, addressing the needs of disabled older people is becoming urgent. This is particularly true for people in countries experiencing conflict or in refugee situations, since it may be difficult or impossible to access appropriate treatment or support.17

Since older people in developing countries often remain economically active throughout their lives because there are no social security programs to support them, they are particularly affected by a loss of income brought on by the onset of disability. When older people act as care givers for a disabled person, such as a spouse or child, their earning power is also curtailed. In both cases, lower income can also result in poorer health, as people cannot afford appropriate health care.

Older disabled people may also face a double burden of discrimination: for instance, a young deaf person may be able to learn sign language but an older deaf person may be denied the opportunity to learn it “at their age.” Some might argue that even official statistics ignore this group, as very few studies of older people with disabilities

17 For more information on mainstreaming disability in emergency and post-conflict situations, please refer to discrimination workshop 4 in this conference report.
have been conducted at all, and those that have been carried out have been done in more developed countries.

So, while many people at the conference believe that disability is a development issue, Dr Yousif put forward the idea that age and disability together also create specific circumstances that must be addressed in development programs. In industrial countries, economic modernization has brought profound changes to the structure of families and communities. It is reasonable to expect that similar changes will occur in developing countries, including falling birth rates, nuclear families becoming relatively more important while extended families have less influence, and population movements from rural to urban areas. All of these factors will have a direct impact on older people’s lives.

Taking this into account, the disability movement could work more closely with development organizations, to promote the inclusion of disabled older people in a wide range of social programs and initiatives. Self-help organizations for older disabled people could be founded and supported, with a remit to address a range of issues from economic support to lobbying for changes in the law.\textsuperscript{18} For organizations or institutional bodies providing emergency relief, it is also important to build the needs of older people with disabilities into service assessment, delivery and monitoring.

To help bring about these positive developments, workshop participants made a number of recommendations:

1. Improve the evidence on hard-to-reach marginalized groups, such as by collecting disability and age-disaggregated data
2. Donors should relate funding and policy decisions to human rights obligations towards older disabled people
3. Prevent disability through appropriate services and poverty reduction programs, and appropriately manage the disabilities that people already have
4. Older women with disabilities must be included in all social and development programs and in government policies
5. Study the impact of conflict on disability, and incorporate disability concerns in peace and post-conflict development initiatives.

Disability in old age is a dynamic process: as age and the burden of disease increase, so does the risk of disability. Also, it is cumulative, as the aging process does not stop once people have become disabled.

\textsuperscript{18} For more information on the role of self-help groups and economic empowerment, please refer to poverty workshop 7 in this conference report.
Poverty reduction is central to the Philippine government’s programs, asserts Richard Arcenio, and disability has also become a central component in anti-poverty programs. Mr. Arcenio was a Sectoral Representative for the Persons With Disability Sector for the National Anti-Poverty Commission (NAPC) Office of the President from 2002–2005. Being chaired by the country’s president gives the NAPC the strength to mainstream disability with the Philippine government, and contribute to poverty reduction strategies. Although the situation for people with disabilities in the Philippines still needs to be improved, this is a step in the right direction, Mr. Arcenio believes.

The Social Reform and Poverty Alleviation Act created the NAPC in 1998 to enhance programs, approaches and strategies that strengthen the partnership between government and the basic sectors. Specifically, it also looks at NGO participation in social reform and strengthens microfinance through the government’s own microfinance initiative and private organizations. People with disabilities are represented through the Disability Sectoral Council, which forms a Sectoral Agenda on each of the NAPC’s six core poverty reduction strategies:

1. Asset reform
2. Human development
3. Livelihood and employment
4. Social security
5. Peace and order
6. Participation in governance.

The agenda then serves as a roadmap for engagement with various stakeholders for the following three-year period.

Mr. Arcenio was also active with PhilCOCHED, the Philippine Council of Cheshire Homes for the Disabled from 2005–2007. Composed of representative officials from 35 Cheshire Homes around the country and other community-based partners, PhilCOCHED supports people with disabilities to develop their skills and knowledge to enhance their participation within mainstream society.

Its work in the Philippines started in the early 1960s with a residential home for paraplegics. Today, it runs programs and services to provide:
1. Educational, food and accommodation support to young students with disabilities
2. Medical and vocational rehabilitation and livelihood opportunities to the poorest of the poor people with disabilities.

PhilCOCHED works closely with Leonard Cheshire Disability, an international non-government organization based in London, supporting more than 250 projects for people with disabilities with local partners, in 54 countries worldwide.

Taken together, the programs of the NAPC and PhilCOCHED represent a two-pronged approach to including disability in development programs. With the government ensuring that disability is included in the development agenda, the groups carrying out inclusive development programs dovetail with government inclusion efforts. This could serve as a model for other countries in which the respective roles of government and civil society in the implementation of inclusive PRSPs have not yet been clearly defined.

Picking up on this issue, the next speaker, Dorothea Rischewski, considered that PRSPs are the most important policy documents in more than 60 low-income countries. The theory is that PRSPs are specific to each country’s needs and have broad stakeholder participation. In reality there may be problems, for example exclusion of democratically elected bodies such as parliamentarians and lack of meaningful participation by community groups. Marginalized groups such as poor people and people with disabilities may also be excluded from the implementation of some programs.

For people with disabilities to participate most effectively, contends Ms Rischewski, disabled people’s organizations must be empowered and all partners – multi- and bilateral development partners, NGOS and community organizations – need to work together. A successful example of cooperation between an NGO and a community organization includes the joint GTZ program with CBM (Christian Blind Mission), Handicap International and local disabled people’s organizations in Cambodia, Tanzania and Vietnam.

Some signs that such a partnership is working include an increase in the strength of DPOs, inclusion of people with disabilities in mainstream organizations and mainstream society, and requests from community groups reaching national policy discussions. In the past, organizations have taken a number of steps to help bring about such change:

1. Awareness training for all stakeholders – through, among other means, the handbook “Making PRSP inclusive”
2. Involvement of government representatives on national and regional/provincial/local level
3. Institutional, technical and political capacity development of community organizations including:
   a. Small equipment
   b. Specific training for the target group (such as sign language training)
   c. Microgrants
4. Inclusive monitoring and evaluation
5. Publications that cover examples of best practice.

In the three phases of development of PRSPs – drafting, implementation, and monitoring and evaluation – input from disability stakeholders is essential. Experience has shown that development actors have often participated in the first phase, but not the last two: to make PRSPs more effective, this needs to change.

One reason for a decline in participation may be an evidence gap between the second and third phases, because of poor monitoring and poor participation by vulnerable groups. Involving local stakeholders at every stage is one way to tackle this. Another way is to involve international NGOs that can bring financial resources, their good reputation with project participants and political campaigning networks, to the whole PRSP process. If bilateral organizations also join in implementation, they can put pressure on national governments for transparency and accountability. The danger is that they do not always focus on vulnerable groups, so some disabled people's particular needs may be inadvertently dropped from their programs.

The best way forward, Ms. Rischewski believes, is to clearly identify all development actors and their specific roles. Efforts for meaningful participation should then be guided by four standards:

1. Rights – implement fundamental rights. The UNCRPD mandates enforcement and institutionalization of participatory rules for inclusive growth strategies (Arts. 3, 32)
2. Structures – establish functioning structures. Stakeholders can help build up and maintain national networks of community organizations in cooperation with international NGOs
3. Legitimacy – secure legitimacy of community service organizations. International NGOs can play a role in assisting in the process of improving democratic representation and capacity among community organizations

The third speaker, Kasahuhn Yilbetal, expanded on these ideas through a case study of PRSPs in Ethiopia. On the positive side, people with disabilities and their organizations participated in the process and raised issues at public forums. DPOs made some efforts to lobby for inclusion, and the National Federation organized workshops for MPs, experts and officials. Unfortunately, however, the issue of disability did not sufficiently feature in the final document. The reasons for this are diverse, including lack of follow-up by DPOs, cost implications, promises not being kept and lack of knowledge on how to include effective measures for people with disabilities.

- In Ethiopia, UN Agencies have formed interest groups, to consider possible actions and strategies to promote inclusion in the national PRSP.
- In the Philippines, people with disabilities attend national level meetings with other development stakeholders every 45 days.
In the face of this, disability stakeholders have decided to try to do their best out of the strategy as it stands, look for ways to address the issue during strategy reviews, and ensure monitoring mechanisms to address disability. Several organizations are working to bring disability into development programs, for instance CBM and the Poverty Action Network of Civil Society organizations in Ethiopia have started an inclusive project. UN agencies have also formed an interest group to consider possible actions and strategies to promote inclusion of disability in the national PRSP.

To empower workshop participants to bring disability into the PRSP agenda, the speakers suggested using some specific tools:

1. Regular media programs on PRSPs and disability
2. Training for experts and policy makers on inclusive PRSPs
3. Developing manuals on how to include disability in PRSP processes (see, for example: “Making PRSP inclusive” by CBM, HI, GTZ)

The workshop participants then suggested three specific calls for action to make PRSPs more inclusive:

1. Stakeholders should lobby the UNECA to facilitate the process to make country PRSPs disability-friendly
2. Stakeholders should form effective partnerships with development partners
3. The capacity of all stakeholders, including civil society, governments and development partners, should be enhanced in inclusive development.

3.2.13 Disability: a public concern, a development issue and a challenge for society – Workshop 13: Mainstreaming disability within the UN

Speakers: Bob Ransom, Ethiopian Center for Disability and Development, Ethiopia
Alessandro Conticini, Senior Chief of Adolescent Development, Protection and HIV/AIDS

Although the Millennium Development Goals (MDGs) make no reference to disability, workshop speaker Bob Ransom believes that international development policy has evolved over the last decade. It now reflects an emerging awareness that disability, and persons with disabilities, must be mainstreamed in development. The former President of the World Bank has even stated that the MDGs cannot be met unless persons with disabilities are included in development and poverty reduction efforts.19

UN agencies engaged in development work, such as UNDP and UNESCO, have clear policies on disability and inclusive development. The UNCRPD now mandates that the

work of all UN agencies should be inclusive. Starting from this base, what is the best way to make this happen within the UN and allied development organizations? Mr. Ransom suggests four strategies to make development truly inclusive:

1. **Create national partnerships for disability and development**

In many countries, DPOs are now taking the lead in raising awareness and demanding respect for the rights of people with disabilities, including access to health services, education and work opportunities.

For such change to occur in the foreseeable future, a larger number of stakeholders must join them and take rigorous action. National partnerships for disability and development, bringing together disability stakeholders – DPOs, disability NGOs, development NGOs, government and concerned individuals – could mobilize a critical mass of concerned individuals and organizations to force change in government and NGO policies and practices.

2. **Strengthen the advocacy role of disabled people’s organizations in inclusive development**

In developing countries, DPOs may not be fully aware of the concept of mainstreaming disability in development. In many countries, individual leaders with disabilities are strong advocates for rights and inclusion, but national poverty reduction programs fail to include persons with disabilities. Where specific efforts have been made, DPOs often find it difficult to sustain inclusive development awareness-raising and advocacy activities. DPOs may spend much of their effort on management and finance, and lack staff experienced in development.

Mr. Ransom further proposes that the slogan “Nothing about us without us” has been misunderstood and misused. Although it is clear that people with disabilities and their organizations must be involved in all decisions affecting them, sometimes DPOs claim exclusive leadership, “ownership,” and control over anything related to disability, excluding others in the process. The slogan does not mean that DPOs have to fight exclusion and advocate for their rights alone. Disability rights, equality of opportunity and inclusive development do not “belong to,” or exist as the exclusive domain or responsibility of, people with disabilities and their organizations. Disability is a public concern, a development issue for government and a challenge for society as a whole. People with disabilities and their organizations need allies – politicians, government officials, economists, lawyers, teachers and development specialists – to achieve inclusion. “Nothing about us without us” is a call for inclusion and collaboration, not exclusion and competition.

The organizational capacity of national and local DPOs must be strengthened, to enable them to advocate more effectively for inclusive development through awareness-raising activities, civil society consultations on development and poverty reduction
plans and programs, and monitoring implementation of such plans and programs at national and local levels. Donors interested in supporting inclusive development should do more to meet the costs of strengthening DPOs and developing trained, paid professional staff to manage them. Inclusive development, as a process and result, will not be achieved unless the capacity of DPOs is increased to play the comprehensive awareness-raising and advocacy role required.

3. Establish inclusive development technical assistance organizations

Although DPOs and disability NGOs often have little knowledge of economic and social development theory and practice, they are expected to influence national development policy and programs. The reverse is true for development agencies and NGOs when it comes to disability – they have little knowledge about disability and persons with disabilities. Inclusive development requires development practitioners to learn about disability, and DPOs and disability specialists to learn about development.

In response, Mr. Ransom proposes a new kind of organization that combines disability and development expertise. It would provide specialist services to help government and NGOs plan and implement inclusive development strategies and practices. Such a technical organization would employ, as disability and development experts, persons with disabilities trained in fields such as development economics, enterprise development, law, community development, water and sanitation, community-based rehabilitation, and other development-related disciplines. Its services would include technical guidance and consultancy services on practical ways, for example, to mainstream children with disabilities in child sponsorship and other programs targeting children, to mainstream women with disabilities in women's empowerment programs, and to mainstream youth and adults with disabilities in skills training and enterprise development programs.

Such an organization is similar to the Centers for Independent Living (CILs) found in America and Europe that provide services to individuals with disabilities, and lobby government and other community organizations to improve access to their services by persons with disabilities and their families. The proposed organization is also similar to the private consulting firms in some countries, run by persons with disabilities, which conduct disability audits of companies and organizations, making recommendations on how to increase disabled people’s access to the organization’s goods and services. The provision of technical expertise and training services is on a fee basis, thus contributing to the financial sustainability of the organization.

4. Hold international development cooperation agencies accountable

Some of the major international development cooperation agencies are not translating their policies into action. There is also little pressure from national governments in developing countries on development cooperation agencies to include a disability dimension in the programs they support.
UN agencies, DPOs, NGOs and governments must hold donor agencies accountable for the practical application and implementation of their inclusive development policies and strategies. This can be done through the proposed national partnerships for disability and development, as well as by individual DPOs and NGOs.

DPOs and NGOs might undertake “inclusive development audits” of the development cooperation programs of donor agencies and UN organizations in a country, examining the extent to which disability and persons with disabilities are included. National poverty reduction programs (PRSPs) might be particularly examined, as they are often supported by a number of donor agencies, many of which have inclusive development policies. The purpose of such audits is to demonstrate the disparity between stated policies of international development cooperation and UN agencies and the reality on the ground – and to demand greater accountability.

The next speaker, Alessandro Conticini of UNICEF, began by suggesting that previous UN failures of the kind described by Mr. Ransom mean that caution is now needed. In Ethiopia, the disability policy framework is good, but it is difficult to legislate against negative attitudes.

The UN technical working group on disability in Ethiopia in 2005–6 stated the importance of raising awareness and advocacy within UN programs. There must be visible mainstreaming, they stressed, and Mr. Conticini raised the example of gender, which has become so mainstreamed that it now sometimes seems to be invisible as an issue.

In Ethiopia, the UN gives grants to organizations working in disability and is considering developing an outreach program for service delivery. Again, Mr. Conticini sounded a note of caution at this positive news: changing attitudes, he said, is more difficult than raising funds.

Social protection remains an important issue. In post-war Europe, social protection programs gave people enough support to move out of poverty and the same kind of thing should happen in Africa. From the donor point of view, the World Bank has US$2 billion available for social protection, but this is not enough to make a significant difference. Wealthier countries and regional bodies, such as the African Union, have a responsibility to help build social protection schemes, including partnerships across countries.

One important way forward is capacity building. Who should do it and how it should be done are the important questions here. NGOs need to put more resources into developing DPOs, Mr. Conticini believes, with real commitment to the process.

The UNCRPD can be a useful tool to help with this. Africa has other national or regional conventions and charters on disability, and those seeking to use a convention to enforce rights should choose the one with the strongest language. Usually this will be the UNCRPD and so it should be used to interpret other human rights instruments.
The issue of whether the UN should create a special agency dedicated to disability received a great deal of attention at the workshop. Mr. Conticini believed it would not be a good idea, as it would be too narrow and interfere with mainstreaming. Other participants thought that it is important to remember that disability is a human rights issue, and supported the need for a UN specialist agency to reinforce the importance of the UNCRPD.

Some participants also commented that the term “vulnerable people” does not follow this human rights approach, and the phrase “disabled people” should be used instead. Also, without involving disabled people in the UN structure to address disability, the correct changes will not be made, they asserted. The same is true for NGOs and other groups, which must mainstream disability within their own organizations before than can advise others on the subject.

Mr. Conticini responded that, unfortunately, development plans talk about vulnerable groups and so the UN has to use this language. He believes that despite the terminology, the UN knows what it needs to do – put disability on the development agenda. Including a strong DPO element within planning and operations, as well as taking on board the human rights message, will allow this to happen.

The workshop’s Chair, Vittoria Beria from the UN Department of Economic and Social Affairs, complimented Ethiopia on its progress on disability, saying that it had acted more quickly than the UN as a whole. Representatives from DPOs added that for these changes to truly take hold, people with disabilities must be empowered to steer and take full advantage of all progress in this area.

Recognizing that driving change was the goal of everyone in the room, workshop participants then called for several action points:

1. Create unilateral leadership for disability and development
2. Strengthen the advocacy role and capacity of DPOs
3. Establish inclusive development technical assistance organizations
4. Hold international agencies to account
5. There should be more support for disability equality training in the UN and more disabled staff employed

The World Bank Disability and Development Team spearheaded the establishment of a Global Partnership on Disability and Development (GPDD), bringing together DPOs, NGOs, donor agencies, UN organizations, international financial institutions, universities, research institutions and interested individuals, to promote inclusive development. The GPDD now has a Secretariat in Washington with a full-time Executive Director, Ms. María Verónica Reina, and implements activities in the areas of education, poverty reduction and disability, and conflicts, crises, and disasters. (www.worldbank.org/disability/gpdd)
4. Ending discrimination is everyone’s responsibility

**Discrimination** noun: unjustifiably different treatment given to different people or groups – Chambers Dictionary, UK

“It is fear that makes disability different....”
– Augustin Agu, UNICEF Ethiopia

Discrimination kills. It also wounds, denies opportunities and impoverishes. Sometimes a subtle problem and sometimes a catastrophe, discrimination must end before full human rights for people with disabilities can be achieved.

Many at the conference were stunned when a Young Voices participant described how a priest who was caring for 60 blind people in Liberia was abducted by rebels, leaving them stuck without food between the rebel and government lines. They were then forced to wander in unfamiliar territory to find food and some were killed by both sides. Such brutality now makes it clear: discrimination against people with disabilities can cause human rights violations akin to some of the worst abuses of modern times.20

On an individual level, the rape of disabled women and girls by HIV positive men, who believe that sex with a virgin can cure AIDS (and that disabled women are necessarily sexually inactive), is another kind of human rights tragedy.21 Even the public murder of women who give birth to babies with disabilities.22 In economic terms, discrimination by employers who prefer to pay fines rather than hire disabled workers can trap whole families in poverty.

A human rights perspective informed debate among panel and workshop speakers and participants. Many called for a shift away from a welfare or charity orientation, to a human rights approach to tackling discrimination. Disability rights must be integrated into all laws and practices, they argue, to catalyze the widespread institutional and personal change needed to overcome the discrimination that now exists.

In politics, this would mean promoting the participation of disabled people within all spheres of government, not just those focused on disability issues. In the media, it means showing the complexity of disabled people’s lives, rather than just reporting their problems. In workplaces, it means bringing to life the principles embodied in the UNCRPD, that all workers have a legal right to be treated equally in every employment setting.

While participating in this conference, sponsored by an NGO and a UN commission, delegates put forward an important challenge: development and emergency relief programs must not inadvertently discriminate against people with disabilities. As actors in this field, we must ask ourselves whether some humanitarian aid projects have actually made the situation worse for disabled people.

This holds true as well for educational institutions, which several speakers identified as being crucial to ending discrimination. India’s 300 universities did not set out to discriminate against people with disabilities, for example, yet not one is currently accessible. The teachers at a special school for deaf children in Uganda may have good motives, but when not one child in a class of 30 passed the first primary school exam, the impact of discrimination within the education system was obvious.

### 4.1 Panel presentations

To set the stage for a comprehensive exploration of how discrimination works and how it can be undone, panel speakers focused on government policy, social policy and the role of the media:

#### 4.1.1 Filling the gaps between policy and practice in human rights

Speaker: Alexia Manombe-Ncube, Member of Parliament, Namibia

If a blind man cannot read the instructions on a condom wrapper because they are not printed in Braille, how can he use one properly? If a woman who uses a wheelchair cannot enter a health clinic, how can she be tested for HIV/AIDS?

The fact that most health service providers in Namibia consider their services to be inclusive, even in the face of the above issues, is one reason why panel speaker Alexia Manombe-Ncube considers discrimination against people with disabilities to be widespread. While much of this is unthinking, as in the above two examples, it has led to poverty and health problems. It is also a cause of one of the most shocking facts about HIV/AIDS in Africa – that people with disabilities have higher rates of infection than non-disabled people.

Ms. Manombe-Ncube is chairman and founder of the Namibian Association of Differently Abled Women (NADAWO) and Namibia’s MP for the constituency of disabled people.
From this, she has come to believe that the best way to combat discrimination is for people with disabilities to become more visible in leadership positions.

Last year, Ms. Manombe-Ncube presented a motion on this subject to the Namibian Parliament. Having received a good response from MPs, the Standing Committee on Legal and Constitutional Affairs has started visiting other countries to learn of their experiences with the participation of people with disabilities at all levels of governance. This consideration will, she hopes, lead to the passing of a law to increase the visibility of disabled people within the government.

This is one of the more striking examples of how the disability movement and government can work together. Other examples in Namibia include three acts guaranteeing rights in several spheres, and the ratification of the UNCRPD in December 2007, making it the fifth country in the world to do so.

Since legislation is becoming comprehensive, the issue now is to speed up the implementation process. The current policy environment focuses on mainstreaming disability issues, making them the concern of everyone rather than just special interest groups. Within the Office of the Prime Minister, the Disability Unit helps ensure that individual actors within each government sector have specific activities to implement, and that they all contribute to the overall goal.

Ms. Manombe-Ncube lists several important messages for those dedicated to ending discrimination against disabled people by increasing their visibility and participation:

1. Everyone, not just those deemed to be specialists, needs to be concerned with disability issues. We must work to increase the ownership of disability issues by many stakeholders, with the goal of mainstreaming disability.
2. People with disabilities must remain the focus of attention in participation, leadership and driving the agenda for action. The UNCRPD embraces and reinforces this argument, which has been made by disabled people for many years.
3. The Convention coming into force does not mean that advocacy among people with disabilities should end. This is just the first phase, which ensures a global standard for approaching disability as both a development and a human rights issue. The next phase of work is to ensure that the UNCRPD and other domestic laws are implemented to serve people with disabilities.
4. The coming period will require concerted efforts to ensure that sufficient resources are made available for full implementation of all relevant laws.

Personally, Ms. Manombe-Ncube has hope for an improvement in the situation for disabled people. Deep-seated negative attitudes are still harmful, and she drew particular attention to the sexual exploitation of women and girls with disabilities. As long as they are excluded from mainstream women’s organizations, or even organizations of disabled people, they remain more vulnerable. For mainstreaming truly to make a difference, then, unrecognized discrimination among the groups trying to change things must also be uncovered and erased.
4.1.2 The role of media in perpetuating or removing discrimination
Speaker: Sorious Samura, journalist and filmmaker

On the day that you read this, in many parts of Africa a woman who gives birth to a disabled child does not need to be told what will follow. She will be called a witch, or evil, or a she-devil. She may be publicly humiliated with her newborn baby and may be stoned to death. Her husband may even join in and his family will immediately disown the baby. When news of this reaches the local media, they will run stories like “Witch stoned to death” or “Another evil one bites the dust.”

These words from Sorious Samura, an award-winning journalist and filmmaker, reflect his grief at the situation for people with disabilities and their families in Africa, “this demanding continent of ours.” Originally from Sierra Leone, Mr. Samura described how he had grown up believing that people with disabilities had special, evil powers.

When he attended high school in Freetown, he and his friends heard that a school for what they called the mentally retarded was being built nearby. The schoolboys used to stone the builders, and when that didn’t work, they beat the children who attended the school. Believing that disabled people had evil spiritual powers, the boys beat them twice as brutally as they would have hit anyone else.

Nowadays, Mr. Samura believes, thinking in the cities has progressed, but beliefs in the rural areas are still as ignorant. And as long as the media portray the views of the attackers rather than the victims, this ignorance will remain unchallenged.

“I am now lucky enough to be a journalist who has a voice to speak up for the innocent,” Mr. Samura said. Living now in Britain, he has come to see another view of disability, where disabled people have jobs and lives and support. The laws that protect people with disabilities in the UK can only be dreamed about in most African countries, even with the new Convention.

The Western media, however, deals with disabled people by ignoring them, believes Mr. Samura. Although they are not thought to be evil, they face another kind of discrimination: they don’t fit into the modern agenda of celebrity, sport and body image. Beckham or James Bond, Naomi Campbell or Britney Spears – disabled people still don’t fit the bill.

To change this, those in the media who care about the situation must tell powerful stories about what is really happening. By making people imagine what life with a disability is like, the media can inspire them to put themselves in a disabled person’s shoes and walk a mile in them.

For disabled people not to be thought of as “other,” they must also tell their own stories. That is why Mr. Samura is proud to be part of Young Voices, the Leonard Cheshire
Disability project to empower young people with disabilities in 18 countries to campaign for ratification and implementation of the UNCRPD. At this conference they have been trained to use video cameras, which they will then take home to film the activities of the Young Voices groups in their countries.

By telling their own stories, the Young Voices participants can help other people understand what their individual worlds are like, and inspire people through their own stories, not for sympathy but for respect. They have already inspired him, Mr. Samura says, to continue his own fight to give voice to the voiceless majority in our world.

4.1.3 **Countering discrimination in the social sector**

Speaker: Javed Abidi, Honorary Director, The National Centre for Promotion of Employment for Disabled People (NCPEDP), India

“In Latin America, less than a third of countries have their constitutions available in Braille. For them, blind people are not citizens.”

− Maria Verónica Reina, Executive Director, Global Partnership on Disability and Development, World Bank

Armed with a journalism degree from an American university, Javed Abidi returned to his native India eager to start work. To his surprise and dismay, it took him six months to find a job and many people told him he had chosen the wrong path. Now Director of the National Centre for Promotion of Employment for Disabled People and Secretary of the Commonwealth Disabled People’s Forum, as well as a respected journalist in India, Mr. Abidi believes these problems were a direct result of discrimination.

Mr. Abidi is now dedicated to breaking down stereotypes of disability. He has headed a campaign in India to ratify the UNCRPD, but met with resistance from some quarters of society and government, which wanted to wait until other countries ratified it first. This, too, he asserts, was a result of entrenched discrimination, but he is proud that campaigners were able to overcome it, and India became the seventh country to ratify on 1 October 2007.

Mobilizing this campaign has also helped influence other government initiatives. India is now implementing its 11th five-year plan, which includes a national budget. The plan now has a chapter on disability, meaning that disability has moved from being the responsibility of the Ministry of Social Justice to being an implicit part of every arm of government. All ministries now need to look at what they have to do and must move away from stereotypes. For instance, access to education has become a fashionable cause, but now the government must also consider things such as access to sport, access to information technology and access for women.

There is still a long way to go in India, however. Considering the education sector, not a single one of India’s over 300 universities is wheelchair accessible, and not one is
accessible for visually impaired students, except for a few textbooks in Braille. Of the thousands of websites now produced in India every year, only six or seven are accessible for visually impaired people. Most deaf people in India never make it to university because deaf children are lucky to get even the most basic education.

This is changing, however. Having recently forced the Ministry to take up the issue, there is now a very clear plan called 2020, which is being implemented in a few universities. Soon some ramps and more accessible software will be installed.

In cities, access has improved in general. For instance, the Delhi metro is totally accessible, new buses will be accessible and many public buildings have ramps. Unfortunately, some other Indian cities cannot match this and the situation in rural areas usually remains poor.

In employment, a law guarantees that 3% of government employees must have disabilities and this, with strong support for the Prime Minister, has resulted in many more disabled people joining the civil service. Last year, for the first time, a blind person became an administrative officer and a deaf person became an Indian Foreign Service Officer, indicating that people with disabilities are entering higher levels of government administration. Unfortunately, there are still no similar laws, policies or incentives relating to the private sector.

Working in parallel to improve opportunities for disabled people is key, contends Mr. Abidi. In India and in many countries, there is a lot of catching up to do. People talk of issues around IT, health, women and children in isolation, but only by working in harmony will we reach our goal. Policy, including firm laws, monitoring and evaluation, is the only way out of the current situation.

4.2 Workshops

4.2.1 Directing traffic on a two-way street – Workshop 1: Filling the gaps between policy and practice in human rights

Speakers: Charlotte McClain-Nhlapo, Senior Operations Officer, World Bank, USA, and former South Africa Human Rights Commissioner, South Africa
Josephine Sinyo, Law Reform Commission, Kenya

Policy and practice form a two-way street – each should influence the other. As Ms. McClain-Nhlapo asserts, participation of people with disabilities in both policy and practice is an essential precondition for sustainable inclusive development.

In this workshop, Ms. McClain-Nhlapo went on to outline how, if development programs apply the clearly defined values and provisions of the UNCRPD, development will be inclusive. Inclusive education is a potent example of how this interaction between
policy and practice can work, and the UNCRPD provides the framework to make that happen.

Government structures, institutions and decision makers can also be part of ensuring that laws and systems are aligned with the tenets of the UNCRPD. Such changes should be inclusive and offer accountability. Beyond this, there must be participation and empowerment of people with disabilities themselves, to influence lawmakers and policy. **Poverty Reduction Strategy Papers** (PRSPs) and the Millennium Development Goals can also be instruments for implementation and policy dialogue towards inclusive development.

Many actors in the disability field – from governments to NGOs – are increasingly making a qualitative shift from a welfare approach, which was often based on charity, to a moral commitment towards empowerment and development of all founded on the UNCRPD. There are many benefits to this approach, including:

1. It is legally enforceable
2. It identifies the duty bearers
3. It empowers the right holders.

To develop policies based on the rights-based approach at all levels, states need to build their own monitoring and evaluation capacity. A robust civil society creates the demand for this approach, as does the engagement of national human rights institutions and members of parliament. Working through a country’s courts, as well as international networks and partnerships, also facilitates the interaction that influences policy development. Workshop participants stressed the importance of ensuring that people with disabilities are involved in this monitoring process, including through involving disabled people’s organizations in policy development.

Within the UNCRPD, Article 33 addresses national implementation and monitoring, while Article 34 establishes a Committee on the Rights of Persons with Disabilities. The Optional Protocol also establishes two procedures to strengthen the implementation and monitoring of the Convention: the individual communications procedure, and an inquiry procedure.

Using the above measures, the process of making the UNCRPD operational demands a clear and coordinated approach to its implementation. In addition to political will, they highlight the importance of a “no gap policy” in which laws, practices and social policy interact. This method also recognizes that even good policies can be misconstrued and create further barriers for persons with disabilities, particularly in relation to social services.

In light of these considerations Ms. McClain-Nhlapo outlined what she considered to be the elements of effective policies. They are:

1. Aligned with the tenets of the UNCRPD
2. Developed in conjunction with disabled people’s organizations
3. Built on best practices
4. Premised on reliable data
5. Implemented by systems and institutions
6. Allocated adequate resources
7. Monitored and evaluated.

For everyone involved in turning policy into practice and vice versa, the process is a learning curve, often on a step-by-step basis. To make the most of the multiple entry points into the process, we need to create forums where practitioners and policy makers can share experiences, identify the gaps, adapt what does not work and find a shared and effective strategy.

Recognizing that the interaction between policy and practice takes place across a range of arenas, the workshop participants called for six action points to facilitate the process:

1. Develop strategies to ensure independent and continuing monitoring and evaluation of people with disabilities’ satisfaction with their involvement in policymaking. This includes the extent of consultation with, contribution to and consequences of, the inclusion of disabled people’s organizations in development of policy initiatives.
2. Identify where we can leverage opportunities to build mutual capacity, create awareness and build strong regional and international networks to bridge the gap between policy and practice. Such networks would include disabled people’s organizations, service providers, governments and others.
3. Source and share evidence-based tools and best practices that will assist in translating policy into practice, such as the Inter-Parliamentary Union Handbook on the UNCRPD. Those involved can also share previous initiatives that might parallel this Convention’s journey, such as items developed to implement the Convention on the Rights of Children.
4. Develop specific tools to support independent monitoring and evaluation of the UNCRPD, along the lines of the African Gender Development Index and People’s Budgeting.
5. Identify methods and approaches that reach, engage and educate people to take action at the local level.
6. Ensure the review of all relevant legislation at the national level, to ensure alignment with the UNCRPD.

Inclusive education is a potent example of how policy and practice can interact to create inclusive development programs. The Millennium Development Goals can also be instruments for dialogue between those who implement them and those who create policies around them.
4.2.2 From quotas to targets — what works to promote employment? — Workshop 2: Discrimination and employment quotas
Speakers: Barbara Murray, Senior Disability Adviser, International Labour Organization, Geneva
Javed Abidi, Honorary Director, The National Centre for Promotion of Employment for Disabled People (NCPEDP), India

What works and what doesn’t in employment quotas? In this workshop, both speakers addressed these questions in relation to systems used in different countries. Put simply, such programs require that employers hire a certain percentage of people with disabilities. The quotas may take various forms, however, including:
1. Binding quotas backed up by sanctions
2. Binding quotas not backed up by sanctions or another effective enforcement mechanism
3. Non-binding quotas based on a recommendation.

In some countries, quotas are set by legislation or regulations requiring employers to reserve a certain proportion of jobs for people with recognized disabilities. If employers do not fulfill this obligation, they may be required to pay a contribution into a central fund used to promote accessibility in workplaces or for vocational rehabilitation. Countries with this type of legislation include many in Europe such as France, Germany and Italy, as well as several in Asia, including China, Japan and Thailand.

Quotas were originally introduced to promote employment for people who became disabled in industrial accidents, and in particular to promote employment for disabled war veterans after the First World War. The laws were based on the assumption that they addressed workers at lower ends of the economic scale. They also assume that disabled people will have lower productivity than other employees, and they make no provision for retraining.

Reflecting an underlying understanding of disability as a matter of impairment, these laws are rooted in the medical model. Enforcement mechanisms often gave the impression that people with disabilities could not be employed on merit and, in some cases, implied that not to meet the quota obligation was a criminal offense.

More recently, some countries (France, for example) have tried to improve quotas’ effectiveness by focusing on the removal of social barriers in the workplace. They also provide a wider range of options for employers, including on-the-job training and apprenticeships.

In a quota levy scheme, such as those in France and Germany, employers may partially meet their quota requirements by contracting for service provision or production with

24 See the section in this publication on Discrimination Workshop 3: “Tackling discrimination in employment” for more information on social barriers in the workplace.
sheltered workshops. Skills among employees remain an issue: in Germany, the quota was recently reduced from 6% to 5% because there were not enough disabled people with the requisite skills available.

Binding quotas with no legal enforcement mechanism, such as in the UK and Thailand, have largely failed: they have now been abandoned in the UK and reviewed to improve effectiveness in Thailand. A non-binding quota system in the Netherlands was also found to be ineffective and was abolished.

India has had a negative experience with quotas, having established a 3% mandatory quota for government employment in 1977. In a study conducted by NCPEDP in 1999, it was found that only 0.5% of government employees had disabilities.

At first, the Indian quotas only covered the lower end of the job market, which, similar to the early European quotas, implied that disabled people were not capable of working at the higher end. Additional job categories within government jobs were added to the program in 1993, but there were still no penalties for non-compliance.

This approach has not been very effective; for instance, a court case was brought against Delhi University because no disabled people were employed there, despite the improved regulations. The court banned any future hiring at the university until this problem was resolved.

The Indian government has also used incentives to promote employment of people with disabilities in the private sector. It had been assumed that multinational companies would follow employment practices from their home countries, but this has proven not to be the case.

During the workshop, Javed Abidi made the case that incentives need to be coupled with anti-discrimination policies and stringent penalties for employers who do not hire qualified applicants because of their disabilities. These two approaches together, he contends, will create an enabling environment for employment of people with disabilities. Both speakers also emphasized that education, through inclusive education systems rather than special schools, and promoting equal access, must also be considered as necessary to promoting employment.
Many workshop participants from Africa were not sure what they could learn from the experiences in Europe and relatively more economically developed countries in Asia. Mr. Abidi responded that quotas’ effectiveness revolved around the system that is adopted and, despite previous problems, he believes that there is no substitute for quotas. One prerequisite to success, he proposed, is having stringent monitoring mechanisms.

Ms. Murray added that quotas have sometimes developed a negative connotation and that non-discrimination provisions in the UNCRPD would transform them into targets. Also, quotas can be expensive to administer, so study would be needed to find out which type yields more jobs in developing countries’ informal employment sectors, which are often the largest segment of their economies.

When countries consider which quota systems have succeeded elsewhere and which they should adopt, they need to consider the following issues:

1. Which people with disabilities should be targeted by a quota system?
2. Should they adopt a standard or a varying quota?
3. What percentage should the quota incorporate?
4. Should it cover:
   a. All employers or just medium and large employers?
   b. All regions and sectors or just some?
5. What options should be open to employers?

Quota systems have tended to succeed when they have been planned in consultation with employers and taken their size and distribution into account. Examples include Austria, where the compensatory fund is administered by a government ministry, which calculates and informs employers of how much they owe, and France, where it is managed by an association of employers, workers, and persons with disabilities. In Poland, tax collectors may collect and distribute levies owed to the national fund from employers, without a court decision.

Trade union support is also important, as is an effective legal base for enforcement and relatively simple monitoring and administration procedures. Offering different options to employers also helps make the system more robust.

Debate now centers on what quota rates should be, and the fact that many employers seem to prefer making a compensatory payment. The overall message conveyed by quota systems about disabled people’s capacity to work may not fit with current thinking in the disability field, possibly leading to an uneasy fit with non-discrimination laws.

After spirited discussion, workshop participants identified the following action points:

1. Stringent monitoring mechanisms are needed to make quotas work

• Investing in systems can encourage quota monitoring.
• Governments must decide which people are considered disabled.
2. It is necessary to work with employers to develop their awareness of people with disabilities
3. Focus on enterprise development in developing countries and make these inclusive from the start
4. Emphasize targets rather than quotas
5. Quota legislation needs to be revised and brought into line with anti-discrimination measures within the UNCRPD.

4.2.3 Social barriers are a more powerful block than economic considerations — Workshop 3: Tackling discrimination in employment
Speakers: Alexander Tetteh, Ghana Society of the Physically Disabled, Ghana
Sophie Mitra, Assistant Professor, Fordham University, New York, USA

In every country in the world, disabled people have lower employment rates than non-disabled people. They also often earn less money. One reason for this, according to the speakers at this workshop, is deeply ingrained discrimination. Exploring studies on disability and employment in Ghana and India, the workshop used these as an entry-point into how lessons learned could inform fair employment initiatives there and elsewhere.

In a wide-ranging survey of employers, people with disabilities, the government and NGOs in Ghana, Alex Tetteh found that 95% of employers did not have a disabled person on staff. It is estimated that people with disabilities comprise approximately 7–10% of Ghana’s population, leading to the conclusion that disabled people are underrepresented in the workforce. The study found a number of reasons for this:
1. Workplaces are not accessible or lack adaptive equipment
2. Some disabled people did not disclose less obvious impairments for fear of discrimination, which might skew the statistics
3. Some families unfortunately also discriminate against their relatives with disabilities, perpetuating a cycle of lack of employment and access.

Among those in work, the study also found that a staggering 92% of disabled people reported facing discrimination in the workplace from other colleagues or employers. This discrimination can lead to underemployment, when disabled people are not given challenging tasks that would help their careers to progress. A 2002 study by Thomas and Hlahla echoes this, finding that social barriers deterred people from seeking job opportunities, such as promotions.

Conversely, 78% of employers reported that the turnover of people with disabilities in their organizations was low compared to that of other workers. While this implies some stability for disabled people, it may also be a side effect of the discrimination faced when trying to find a new job.

25 Daniel Mont, UN Conference Center, Addis Ababa, Ethiopia, 22 May 2008
Perhaps unexpectedly, given the other findings, the study showed that people with disabilities tend to have higher educational attainment than the population as a whole. Sadly, in light of the other statistics, this may be interpreted as a further indication of discrimination, since people with more educational qualifications usually have more job opportunities, not fewer.

Overall, the study concluded that social barriers (discrimination) are the main cause of unemployment among disabled people in Ghana, with access problems making the situation worse. Further research should therefore study how the social and physical work environment could be altered, to help it support disabled people in the workplace.

Mr. Tetteh also recommended that national disability legislation be strengthened, to focus on helping people find and remain in employment. This could be achieved in part by an expert body to advise employers, and a national awareness campaign to sensitize managers about disability and encourage disabled people to request the support they need.

Half a world away in India, a study in 15 villages in Tamil Nadu by Sophie Mitra and her colleague Usha Sambamoorthi, set out to find out whether, and by how much, disability impacts on wages for rural work. Their research is timely because India has had the Persons with Disabilities Act since 1995, which reserves 3% of places in government employment, government educational institutions and poverty alleviation programs for people with disabilities. It also developed a program to pay unemployment allowance to persons with disabilities registered with the Special Employment Exchange for more than two years, and who could not be placed in any paid occupation. In 2002, the employment rate for people with disabilities across India was only 60% of that of persons without disabilities, indicating that the Act’s goals have not yet been reached.

The research studied households that both did and did not include people with disabilities, and also gathered data on the type and extent of people’s impairments. Questions on education levels, work experience and caste were included to refine the data.

Findings were unequivocal: unadjusted hourly wages were 11% lower among persons with disabilities compared to those without disability. Results reported in another paper.
suggested that disabled people might fare worse than their non-disabled counterparts when it comes to accessing employment.

In a rural setting, a gap of this size is significant for individuals and families. To provide full economic equality for people with disabilities, it would need to be addressed by government policy. Dr. Mitra contends, however, that we simply don’t know what policies best impact on the deeply embedded attitudes that contribute to such unequal treatment. Policy makers and researchers alike should thus focus on understanding this important issue.

Together, workshop participants called for the following action points to combat discrimination in employment:

1. Campaign for the appropriate national legislation on the employment of people with disabilities
2. Robust data and longer-term research are needed to keep the momentum going and promote employability among people with disabilities
3. Everyone involved – employers, policy makers, and people with disabilities themselves – needs education and sensitization on this issue.

4.2.4 When the line between victims and perpetrators is blurred — Workshop 4: Discrimination in emergency situations, a consideration of policy and practice

Speakers: Dr Maria Kett, Assistant Director, Leonard Cheshire Disability and Inclusive Development Centre, University College London
Daintowon Pay-bayee, Student and Young Voices Participant, Liberia
Bekele Gonfa, Director, Landmine Survivors’ Network, Ethiopia

Who deserves more support after a conflict: a man who lost a leg in combat or a child disabled by polio because of disrupted vaccination services? Both deserve whatever support they need, argued Dr Maria Kett in her workshop presentation, Disability, Discrimination and Conflict: What happens next?

This issue has become urgent in Sierra Leone and Liberia, which both suffered violent conflicts in the 1990s and now face similar pressing problems. In both countries however, some international responses to the conflicts and recovery may inadvertently favor the former soldier over the child.

Dr Kett argues that this imbalance can be caused by discrimination, albeit often unintentional. Particularly in the acute emergency phase, humanitarian responses may simply not take disabled people’s needs into account. Examples of this might include inaccessible sanitation facilities within displaced people’s camps, and food distribution in areas that are difficult for disabled people to access. This and the “special needs”
approach, which may not address disabled people directly, does not work, contends Dr Kett. Disability must be mainstreamed in humanitarian aid, so that all areas of emergency intervention become accessible to everyone, regardless of any disabilities.

This is particularly crucial in countries where disabled people are already openly discriminated against, as in Liberia. Workshop speaker Daintownon Pay-bayee described how disabled people were sometimes killed by civil war soldiers “to end their suffering.” In one case, some blind people became abandoned between two warring factions when the priest who was running a center for blind people was abducted by the rebels, and some were killed. Survivors managed to reach a Catholic compound where they met with government officials, who arranged a ceasefire to allow the blind people out, and called on the rebels to stop killing people with disabilities.

Given this level of human rights abuse, in and after civil conflicts it may not be useful to make a distinction between people who are or are not deemed to be vulnerable. Dr Kett argues that in civil wars, for instance in Liberia, the lines between ex-combatants and civilians, and between victims and perpetrators of violence, are not always clear. While not denying they have a role in the immediate post-conflict period, rather than spending vast amounts of money on projects to reintegrate or rehabilitate wounded former fighters (which rarely include disabled people), it may be more effective to use donor funds for broader development programs, such as inclusive job creation, infrastructure development and other priority projects.

For example, in the immediate aftermath of the conflict in Sierra Leone, many NGOs focused on the very visible war wounded and amputees, offering rehabilitation services, prosthetics and resettlement camps. Because they were often located some distance from urban areas, it was difficult for people living in them to find work or go to school, leaving such programs unsustainable in the long term.

Yet Dr. Kett’s research has shown that people who were not wounded by the war, but perhaps became disabled because of disrupted health services, prefer to live in such communities. One group of people with polio in Kono, Sierra Leone, even started their own community to support each other, all of which suggests a lack of service provision for this group.

In Liberia, people with visible impairments are assumed to be former combatants who “deserved what they got.” Yet in reality, it is often impossible to judge how someone came to have impairment. None of the country’s disarmament, demobilization and reintegration programs had a disability component in the early stages.

This has, in part, left disabled young people with little option but to beg on the streets of the capital, Monrovia, and sometimes to be denied access to social services and development programs, regardless of the cause of their disabilities. This comes in the wake of a survey by UNICEF and Liberia’s umbrella organization for disability that found that in some parts of the country, 16% of the population is disabled.
If aid programs perpetuate the idea of deserving victims, they may ultimately hinder broader inclusion in future development. Donors and implementing agencies must therefore rethink how aid money is allocated in the field, as highlighted in Article 11 of the UNCRPD. In a conflict or post-conflict country, the starting point is that everyone must be considered affected.

Ms. Pay-bayee echoed another point made by Dr. Kett: many countries, including Liberia, still have no disability rights legislation and thus no opportunity for legal redress. This is unlikely to change soon in Liberia, considering that the 2008 census did not include any questions about disability, and the country will have no statistics to use in planning service provision or formulating new laws.

There is also outright discrimination there against disabled people in employment. People may be turned down for jobs because of their disability, rather than considered in relation to their qualifications for the position. Even within an NGO setting, Ms. Pay-bayee has experienced being ignored in meetings until she protested, at which point people listened to her comments, but did not record them.

For this reason, Dr. Kett concluded that it might be beneficial to form an inter-agency committee on disability at UN level, which specifically addresses the needs of disabled people in and after emergencies, and gives guidelines for humanitarian organizations. This would help facilitate equality of treatment and opportunity for disabled people, both during and after an emergency. One of Dr. Kett’s main points is that the stages within a conflict – from pre-conflict, to active conflict, to post-conflict – are hard to separate, and this gets even more difficult once the acute emergency phase settles. Conflict is therefore best seen as a continuum, and responses should be tailored accordingly.

This was carried further by Bekele Gonfa, Director of the Land Mines Survivors’ Network in Ethiopia, who contended that landmine survivors need psychosocial as well as physical support at the time of injury and afterwards. His organization has found that a multi-faceted approach works best, including support for:

1. Physical needs such as worry over physical appearance
2. Emotional needs such as depression
3. Social needs such as acceptance and inclusion in the wider society
4. Economic needs.

This integrated strategy helps people deal with current problems and plans for the future, and involves family members, friends and the wider community. Peer support, normally within a school or university, is their preferred way to achieve this for younger people.

The disabled person needs special care and attention at the time of the trauma, and issues have to be addressed particularly urgently at this initial stage. Interventions should be conducted not by professional counselors, but by other people who have gone through the same trauma and finally succeeded in getting their lives back on
These peer supporters could be volunteers or trained persons who can help by mentoring, listening, sharing their own experiences or counseling, as well as referring people to other support initiatives. Some peer supporters also work in hospitals, when their experience can be extremely helpful to people with new injuries.

Helping people access their rights is one of the program’s ultimate goals. It includes training about basic rights, help in claiming them, providing information about disability law and policies, and help with reintegrating people with disabilities into the community.

The impact of the whole program can be profound, supporting people to continue with their lives socially, personally and economically. They often find it necessary to reassure people that they can still marry, have children, support themselves and their families and pursue various careers and other activities. Those receiving support can also go on to become peer supporters themselves.

Peer support is less effective with people who have lived with the injury for many years, or have become dependent on others or support programs. This is also true for people with mental health problems and secondary traumas, such as family or economic problems. Finally, it should be very clear that peer support is neither the only remedy nor a replacement for other services, such as medical care and rehabilitation.

Mr. Gonfa recommends that every government include the peer support approach in its recovery and rehabilitation programs for people with disabilities. They can also encourage various service providers to run such services and fill the gaps.

Recognizing the importance of making humanitarian aid and support inclusive from the start of an emergency, workshop participants called for governments and other organizations to take action on the following issues:

1. Mainstream disability in humanitarian aid programs, both before and after conflicts and other emergencies, to remove unintended discrimination against people with disabilities
2. Consider pre- and post-conflict situations as a continuum and support people with disabilities throughout development interventions
3. Post-conflict countries such as Sierra Leone and Liberia must ratify the UNCRPD and act on it
4. Aid and money should go to families as well as individuals in conflict situations
5. Invite people to see for themselves the richness of disabled people’s lives, including people who don’t share our views, so that they can change their attitudes
6. The UN must follow its own rules
7. Focus on and include learning disabilities in guidelines for emergency situations
8. Ensure that Article 11 in the UNCRPD is followed, and also look at other articles when considering long-term rehabilitation.

### 4.2.5 Lack of education: a major cause of social exclusion – Workshop 5: Perspectives on discrimination in the education sector

Speakers: Professor Xiaoyuan Shang and Jiawen Xie, Institute of Social Development & Public Policy, Beijing Normal University, China
Ambrose Murangira, Chairman, Uganda National Association of the Deaf, Uganda

The personal stories of two young people in different countries both raise the same question: what keeps children and young people with disabilities out of formal education? In general terms, the titles of this conference’s key clusters – lack of access, poverty and discrimination – offer a fairly complete answer. On a personal level, the daily indignities caused by discrimination can be the most discouraging problems for potential students and their families.

This was borne out by Professor Shang’s research in Jiangxi Province, which found widespread discrimination against disabled children. In this workshop, Professor Shang described how China has approximately five million disabled children, 80% of whom live in rural areas with poor services.26 Among abandoned children in state children’s welfare institutions in large cities, approximately 90% have disabilities.27

The current support system for disabilities in China assumes that the main unit of support is the family. Yet fast-moving and broad demographic and social changes have reduced families’ capacity to care for children with disabilities. This has not yet been supplemented by the public sector, and provision for disabled children in practice is rudimentary.

One effect of this is that the ratio of children with disabilities who are illiterate or do not attend school is much higher than that of children without disabilities. This is even worse in urban than in rural areas.

Professor Shang contends that for children with disabilities to achieve their right to an education, a child disability rights framework is needed, and her study explains how this might work. A framework would cover:

1. Right to life, protection and care, including the right to live with their family
2. Right to economic security through economic activity, social security and welfare provision

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26 China Disabled People’s Federation, 2007
27 PED JICA, 2002
3. Development rights to health, education and disability support
4. Participation rights.

Set in a small, poor rural county in Jiangxi Province, the study explored whether disabled children receive any public support and measured discrimination against children with and without disabilities. The qualitative research began with an in-depth investigation of Maomao, a 15-year-old boy with a physical disability and epilepsy. There were also repeat visits with several other families of children with disabilities, which included in-depth interviews with the children’s parents, teachers, classmates and other relevant people.

Looking at Maomao’s situation within each of the pieces of the framework, he was discriminated against from the beginning within his own family, who sent him to live with his grandmother rather than care for him with his brother at home. His right to economic security was not met, because the family’s poverty meant that they did not pay for special education and disability treatment, which may have contributed to the failure of his schooling.

In a mainstream school, Maomao experienced discrimination in attempting to exercise his right to an education. These included access problems, lack of help and, at worst, neglect. In China, discrimination against children with disabilities in schools could be attributed to the current performance evaluation system conducted in education sectors, thereby denying them the third piece of the framework.

After years of teasing, accusations of time wasting and other blocks to his learning, Maomao has now withdrawn both from school and other children. With few friends and poor communication skills, his right to participation has been curtailed. The impact of social discrimination on his personal development has been large in terms of his behavior, cognitive ability, and possibly physical capabilities.

Cumulatively, this discrimination has worsened the outcomes for both the child and his family as he has grown older. Chinese law expressly prohibits discrimination against children with disabilities, but without formal support for families, children are placed at risk of serious neglect and a lifetime of social exclusion. Professor Shang’s study concludes that the implication for policy development is that a combination of support for families, access to mainstream services and specialist care is required for disabled children to experience equal rights.

Many similar observations were then made by Ambrose Murangira from Uganda, who was born hearing, but became deaf as a result of having mumps at age 10. Mr. Murangira now holds a BA in Social Work and Social Administration. He is pursuing a master’s degree in Social Sector Planning and Management and is very involved in disabled people’s organizations in his country. His situation could have been very different however, were it not for his and his mother’s determination.
Special schools in Uganda for deaf children have a low standard of teaching and learning. For instance, when 30 deaf children from a special school took primary leaving exams in 2007, not one passed the first level exam. Mr. Murangira decided to stay in mainstream school and managed to pass his primary examinations. After an aborted attempt at becoming a shoemaker, which he hated, he decided to go to a mainstream secondary school. Since there were no sign language interpreters available, he always sat in the front row and copied notes from a friend. To challenge himself further, he transferred from a rural to an urban school for the final two years.

Discrimination was at the heart of why Mr. Murangira decided to stay in mainstream school, and why he had problems studying there. Had he joined a special school for deaf children, he worried that he would lose his friends and fail his exams. Choosing to advocate from within in a mainstream school, he did sometimes feel left out because of language problems. Teachers would ask other students to give him information and he would see other students enjoying a laugh and not be able to join them. Once, he was even listed as “Deaf” in the school sports team.

Now on track to become one of the only deaf people (approximately 600,000 of Uganda’s 30 million people are deaf) in his country to hold a master’s degree, Ambrose called for people with disabilities to be represented at all levels of student governments and organizations. Without this kind of integration, he contends, discrimination will not end and thousands of people will lose their opportunities for education and advancement in society.

Taking the conclusions of both of the speakers into account, workshop participants called for the following:

1. Parents should be involved in making government policy
2. Organize parents to be involved in decision making.
3. Advocacy and lobbying are needed to help existing education systems change to include children with disabilities, and prevent abuse
4. Lobbying in specific fields can include pressure to develop national or international sign languages
5. People with disabilities should be represented within student bodies
6. Specialized departments should be created within learning institutions, to support learners with disabilities
7. African universities need support to establish campus offices (under the supervision of the Dean of Students), responsible for disability affairs as well as recruiting qualified personnel to mainstream disability issues.

- China has approximately 10 million disabled children, 80% of whom live in rural areas with poor services.
- When 30 deaf children from a special school took primary leaving exams in Uganda in 2007, no one passed the first level exam.
We have today, contends workshop speaker Monica Mbaru, “consensus that the ban against discrimination based on sex, race, nationality, religion, ethnicity or any other status is now a peremptory norm of international law practice and application.” This agreement comes thanks to previous UN human rights conventions, including the Convention on the Rights of the Child (CRC) and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). The question now is: how can the UNCRPD use the experience gained in implementing these huge advances in the practice of human rights law and other forms of social change to improve the situation for people with disabilities?

The first step is to recognize the paradigm shift embodied in Articles 2 and 5 of the new convention, from considering people with disabilities as objects of charity, to citizens with rights and the ability to make decisions based on informed consent.

When using the new international Convention in cases relating to people with disabilities, it is important to remember that it transcends national laws, which may even contradict it. In Nigeria and Tanzania, for example, there are laws that prohibit discrimination on the basis of gender. Other laws, however, allow men to confer citizenship on their foreign spouses through marriage, but do not allow women to do the same. This kind of contradiction is directly contrary to CEDAW and, from a legal point of view, should not exist. As such, it is an issue that gender equality campaigners in those countries could address, and from which disability campaigners can learn.

Article 4 of the International Covenant on Civil and Political Rights, which came into force in 1976, already requires “Equality of treatment... without distinction of any kind...” This should make current human rights abuses against people with disabilities, such as denial of educational opportunities, segregation and imposition of physical barriers, illegal now. Since we know that these discriminatory practices still occur, Ms. Mbaru believes that the way to make a UN Convention effective is to ensure that national laws that follow it are fully applied. Infringement of rights must incur penalties, and courts need to be sensitized to understand the implications of the new Convention. All of this applies specifically to effectively implementing the UNCRPD.

Gerison Lansdown then explored how lessons learned from implementing the CRC may be applied to the UNCRPD. Like the UNCRPD, the CRC was ratified very quickly, which lent force to the idea of children’s rights as a human rights principle. Globally, it benefited hugely from a UN body, UNICEF, adopting the CRC as its mission. Being present in every country in the world, UNICEF can work closely with governments to support the CRC’s implementation.
A group of international NGOs, the NGO Group for the Convention on the Rights of the Child, also established itself in 1983 to seek to influence the drafting of the CRC. After it was adopted in 1989, the group switched its focus to monitoring and implementation. It now works to:

1. Raise awareness of the Convention
2. Promote and facilitate implementation of the Convention
3. Facilitate communication between the Committee on the Rights of the Child and the NGO community
4. Promote cooperation and information sharing on the CRC within the NGO community
5. Draw up policies and strategies and undertake action in fields covered by the Convention
6. Contribute to the monitoring work of the Committee on the Rights of the Child
7. Facilitate the creation and support the work of National Coalitions for the Convention on the Rights of the Child
8. Develop tools and guides for advocacy

The group has made a large impact by supporting NGOs at national level to form coalitions that produce integrated shadow reports to the Committee on the Rights of the Child, the body of independent experts that monitors implementation of the CRC by its state parties. Key international NGOs working with children have also adopted the CRC as their mandate, including Save the Children and Plan International.

In programs for children, the CRC has been influential in developing child rights-based approaches, and an increasing focus on advocacy in place of service provision. There is also a growing understanding among NGOs about the importance of engagement with global institutions.

As an example of how NGO engagement with the CRC works in one country, Ms. Lansdown examined the model used in the UK. In 1992, a dedicated secretariat, the Children’s Rights Development Unit, was established, focused on promoting implementation of the CRC. It gained a membership of hundreds of interested organizations and bodies and has adopted strategies for its members on monitoring compliance, promoting children's participation, implementation across civil society, raising awareness and advocating for more effective implementation.

Their policies and research results are fed back to the Committee on the Rights of the Child, providing a two-way flow of information and guidance. The group has also progressed to promoting children's involvement in lobbying for their own rights, an approach that could be widely used within the disability rights movement to advocate for ratification and implementation of the UNCRPD.
To bring the UNCRPD closer to full implementation using successes and avoiding failures from past conventions, workshop participants called for the following action points:

1. Ensure that disability issues and rights are recognized, protected and enforced by laws that carry penalties if they are infringed
2. Ensure full access to national and international courts, because access to justice through the courts is the main vehicle through which the above can be achieved
3. The UN must provide strong support for ratification and implementation
4. There is a key role for civil society organizations in monitoring and promoting implementation. To build their capacity for this, grassroots NGOs and disabled people’s organizations need support and information
5. NGO collaboration at national level strengthens impact
6. Establishing accountability mechanisms is essential
7. Self-advocacy is vital in changing attitudes and awareness.

4.2.7 Without pity: Disabled people deserve fair coverage – Workshop 7: The role of media in perpetuating or removing discrimination

Speakers: Bosco Wani, Leonard Cheshire Disability Young Voices Representative, Sudan
Richard Rieser, Director, Disability Equality in Education, UK

“Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention…” This quote from Article 8 of the UNCRPD makes it clear: the media must now give disabled people the full range of coverage that they and their work merit.

Historically, this has been far from true. Speaking from a European perspective, Richard Reiser explained how the media traditionally portrayed people with disabilities as pitiable, comic, evil or triumphing over adversity. These stereotypes derive from myths or mistaken ideas from religion and culture, and must be challenged, particularly the outdated belief that disabled people are not capable of living full lives. Bosco Wani added that in Africa, the media has played a major role in perpetuating discrimination against people with disabilities, and added to the denial of human rights.

Both speakers, however, believe that the media portrayal of people with disabilities can change. Most of the negative stereotypes are in fiction – folk tales, stories, plays – and can be repeated in books, films, television and comics. Mr. Rieser suggests a multi-dimensional plan for those in the media to change this:

1. Shun one-dimensional characterizations. Portray disabled people as having complex personalities capable of a full range of emotions

28 Mr. Rieser has written a book and website that further analyze how disabled people have been shown in Western Cinema. For those interested in exploring this further, the web address is www.bfi.org.uk/disablingimagery and the book is available from www.diseed.org.uk.
2. Avoid depicting people with disabilities as always receiving. Show disabled people as equals giving as well as receiving
3. Avoid presenting physical and mental characteristics as determining personality
4. Refrain from depicting disabled people as objects of curiosity. Make people with disabilities ordinary
5. Do not ridicule impairments or make them the butt of jokes
6. Avoid sensationalizing disabled people, especially as victims or perpetrators of violence
7. Refrain from endowing people with disabilities with superhuman attributes
8. Avoid overly positive plots that make the disabled person’s attitude the problem. Show the social barriers that keep disabled people from living full lives
9. Avoid showing disabled people as non-sexual. Show people with disabilities in loving relationships and expressing the same range of sexual needs and desires as non-disabled people
10. Show people with disabilities as an ordinary part of life in all forms of representation
11. Most importantly cast, train and write disabled people into scripts, programs and publications.

Some of these recommendations were developed in reaction to a European Union conference in 2003. Speakers revealed that less than 1% of television coverage included disabled people, despite the fact that 10% of the EU population is disabled. Their portrayal was also predominantly negative.

Twelve disability organizations from nine European countries then created a two-year project and website, with support from the EU Directorate General for Employment, Social Affairs and Equal Opportunities. They held workshops and conferences and helped develop national plans to address these problems. People in any country can benefit from their experience and plans, which can be accessed and downloaded through the website, www.mediaanddisability.org.

Mr. Wani also shared how the Young Voices projects in Africa have used radio to help educate people with disabilities and the general public about their rights. The project started when Mr. Wani visited four towns in South Sudan and identified 3,000 people with disabilities and their family members. To promote changes in attitude towards disability and self-esteem among disabled people, he and the other project participants developed a multi-media campaign in the country. Radio was at its heart because it is the most widely available broadcast medium in South Sudan, and Mr. Wani secured a weekly radio slot to speak on the rights of people with disabilities. This was backed up by dramas on Sudanese state television, as well as posters, T-shirts, public demonstrations on disability rights and targeted articles in newspapers. Mr. Wani and the other Young Voices participants also hope to start a website to campaign for disability rights.
The workshop participants agreed that radio is the best media tool to use for advocacy, particularly in Africa where people may not have as much access to other broadcast or print media. When contacting the media, it is also best to approach editors, as the journalists themselves often have little say when it comes to the subjects they cover.

Participants then came up with a list of recommendations on how to change or increase media coverage of disability:

1. Study the background of journalists or media outlets when dealing with them – this can be done through sensitization workshops and lobbying their training institutions
2. Journalists or media that portray disability positively should be recognized and given credit, while those who portray it negatively should be challenged through the media
3. Make all forms of media accessible to people with any disability
4. Strategically identify people with an interest in disability who work within the media, to build better partnerships
5. Target editors when dealing with media outlets
6. Lobby for the employment and inclusion of people with disabilities in media institutions, and empower them to deal with any discrimination they encounter.

4.2.8 Everyone has the right to serve his country — Workshop 8: Advocacy and campaigning to change attitudes

Speakers: Phitalis Were Masakhwe, Campaigns and Advocacy Manager, Leonard Cheshire Disability, East and North Africa Regional Office
Alexander Phiri, Director, Southern Africa Federation of the Disabled (SAFOD), Zimbabwe

“Seek ye the political kingdom first and all else will follow.”
Kwame Nkrumah, first Prime Minister of Ghana, the first African country to become independent

Phitalis Were Masakhwe opened the workshop by asserting that politics – and those who captain the political ship – have the power to override all other forces in society such as economics. The right of people with disabilities to vote and participate in political life was articulated with that of every other adult in the 1948 Universal Declaration of Human Rights. Article 29 of the UNCRPD, which states that governments must ensure that people with disabilities can vote and provide the necessary support, such as accessible polling places and ballots, has strengthened it.

In addition to voting, disabled people have the right to run for elected office, and there have been disabled MPs in Kenya for ten years. For those who do not choose to run but want to influence, the UNCRPD should also make campaigning and advocacy more accessible. One way to be politically active in the field of disability is to work with
NGOs and associations concerned with a country’s public and political life, and in the activities and administration of political parties. Another is to form and join disabled people’s organizations, to represent people with disabilities at international, national, regional and local levels.

For a disabled person who would like to enter politics, Mr. Masakhwe asserts that the force of change must be inside oneself; outsiders such as politicians or disability rights supporters can only provide enabling conditions. Potential disabled politicians need to develop the knowledge, experience and confidence for political battle. To help them understand the dynamics and intricacies of politics, he recommends creating enabling conditions through:

1. Partnership and collaborative action
2. Regular and consistent disability sensitization of the community and its leadership
3. Investing in civic and legal literacy and rights education, including lobbying and advocacy skills development of disabled people and their parents/friends.

Barriers to this enabling process include weak disabled people’s organizations, lack of resources (politics costs money), low education levels and poor self-confidence. To overcome these will require some fundamental changes to a range of institutions that now discriminate against people with disabilities. These include:

1. Advocacy and lobbying for quotas and other mechanisms, to ensure that everyone can be included in politics
2. Financial and other material support to candidates with disabilities to run an election campaign
3. Reforms to enable participation of people with disabilities within individual political parties
4. Organized effort by the media and other general public to champion political engagement
5. Support disabled people to be exposed to new knowledge and experience
6. Support disabled people to realize “their political arsenal.”

Why go through all of this? An international overview of the impact of disabled politicians and disability policy bodies on governance concluded that having disabled individuals in positions of governance is clearly having impact. People with disabilities in government positions also report that legislation and programmatic improvements have aided the situation of disabled people in their respective countries.

Though perhaps less quantifiable, they also list heightened awareness and increased understanding of disability issues among their non-disabled colleagues as another positive impact. Many report that their non-disabled peers have begun to consider all issues through a new “disability lens,” and as a result, they have developed new allies in the fight for equal access and inclusion. They see themselves as role models who could inspire new generations of people with disabilities to enter public service.
Before even being able to begin public action, however, argues the second speaker, Alexander Phiri, embedded attitudes towards disability in the community must change. Even today some cultures kill disabled children, while others are hidden and thus unable to receive support. Perhaps most insidious is discrimination among disabled people themselves, who have internalized other people’s negative attitudes.

The way forward, Mr. Phiri believes, is to begin to change attitudes at the family level and progress to schools and community structures. Working in concert, this attitude change can help tackle the discrimination that might keep people with disabilities from full engagement in political life.

4.2.9 Inclusion means working with, not working for — Workshop 9: Youth engagement

Speakers: Gayatri Kembhavi, PhD student, University College London, UK
Ephraim Segone, Leonard Cheshire Disability Young Voices Participant, South Africa

“What distinguishes this large group of youth are not their common needs, but the fact that these needs continue to go so largely unmet.”

— Nora Groce, Professor, Leonard Cheshire Disability and Inclusive Development Centre, University College London

In Western countries, adolescence marks a gradual progression from childhood to adulthood. In lower income countries, this shift is more likely to be defined by entering the workforce or marriage. Young people who do not work or marry because of disability may then remain in a kind of perpetual childhood, denied the rights and benefits afforded to adults. While the needs of children and adults with disabilities have been widely studied and defined, those of adolescents (aged 13–16 years) and youth (aged 16–19 years), have not.

Gayatri Kembhavi’s research in Bangalore, India, with 37 young people with disabilities, set out to begin to change this by studying what adolescents with physical disabilities themselves believe prevents or facilitates their participation and inclusion in their communities. Using participatory techniques, it also included research with their parents and non-disabled adolescents. Each of the 37 young people was given a camera to record:

1. Things in their lives that made them happy, gave them a sense of pride or that they enjoyed
2. Things in their lives that made them sad

Article 29 of the UNCRPD states:

Parties shall guarantee to persons with disabilities, their political rights and the opportunity to enjoy them on an equal basis with others, in accordance with national laws…

3. Things in their lives that made them angry or frustrated
4. Things in their lives that they would have liked to change/make different.

They also received some training in how to use the cameras, but were told that they could decide themselves what to photograph. One week later the photographs were developed, and the young people met with the researcher to share and discuss them with the group.

Despite doubts from the NGOs through which the adolescents were recruited about whether they could handle taking pictures, all were able to take usable photographs. Participants then placed the photographs into one of four categories: “Happy,” “Sad,” “Angry/Frustrated” and “Want to Change.”

The adolescents’ photographs mainly focused on family, friends and other important people in their lives. Many participants however, focused on environmental issues and concerns. One adolescent photographed a large pothole in the road as “something that makes you angry,” because it was a major barrier that restricted the mobility of his classmates who use wheelchairs. Other examples of environmental barriers were the stairs leading up to a video game arcade. The participant said that the stairs were an example of “something that makes you sad” and “something that makes you angry,” as they prevented him from being able to engage in an activity that he enjoyed. Another participant took a photograph of an empty lot that was full of garbage, as “something that makes you angry or frustrated.” Seeing piles of waste made him angry about the environment in which he lived, and it was something he would like to change. Other environmental concerns photographed were the over-use of plastics and wasting water.

The adolescents with disabilities commented that they were excited to contribute to the research, and that they were proud to be given the responsibility of using the cameras. Another important benefit of the photography approach was that it facilitated discussion, especially among those participants who were more shy or quiet, because they had something specific to discuss.

Engaging adolescents and youth does not simply involve asking them questions about their lives, Ms. Kembhavi concluded. Merely asking questions constitutes research “on” adolescents, not “with” them. Inclusion such as this will allow adolescents with disabilities to engage with their environments and influence the services programs that exist to help them. It also forms a first step towards the adult roles and responsibilities to which they aspire.

This engagement was also the focus of Ephraim Segone’s presentation. “Aren’t we the public?” he asked, when querying why “public” buildings are not accessible to people with disabilities. As a Young Voices participant, he called on all the young people at the conference and those back in their home countries to say “here we are; we are ready to make changes.”
The title of this conference, “a call for action on poverty, discrimination and lack of access” is, Mr. Segone believed, also a mandate for youth engagement. Moving from discussion to action can be very motivating for young people who have the energy and will to change society. As this conference calls for action, it also implicitly gives an assignment to each Young Voices participant: to fight the challenges that come their way. Unity and collective effort will be important, as will a vision of the desired future. Both have power in themselves, and Mr. Segone looks forward to working with other young people to implement all the things we have discussed at the conference.

To support the kind of engagement through which young people can take more charge of their lives and contribute to change for disabled people, workshop participants called on those involved with young people to:

1. Provide information on the rights of people with disabilities and on the Convention in an accessible way, especially to empower young people with disabilities to claim their rights
2. Influence disabled people’s organizations to include young people with disability into their membership, and in the design of their advocacy campaigns.

Successful adulthood is enhanced by successful participation in adolescence. The World Health Organization defines participation as “involvement in a life situation”.

Successful adulthood is enhanced by successful participation in adolescence. The World Health Organization defines participation as “involvement in a life situation”.
5. **Access: an essential human right**

Of all human rights, access is one of the most fundamental. In every sphere of life – transportation, employment, ICT, water and sanitation, investment, family and relationships, education, health care, government, civil society, religion, culture and leisure – access is vital for participation.

Access is also unique in being an inclusive and holistic concept that has different meanings in different contexts. Having only one type of access in any field is not enough to ensure full participation of people with disabilities. Conference panel speakers and workshop presenters illustrated that people may have access to one element of justice systems, education, work and ICT, but face barriers in accessing other areas. Plans to increase access, too, may improve one way into a system, but either not affect or even damage another path. In addition, people with disabilities, like all people, are individuals, and each has different access needs.

Measures such as laws, programs affirming rights, service provision and social benefits cannot work in isolation: other needs must always be considered and addressed. These include modifications of physical surroundings, communications systems, legal structures, medical and rehabilitation services and, perhaps most crucially, attitudes. It also includes cooperation between the people and organisations that plan, fund, implement and evaluate these initiatives.

The following pages summarise the key arguments and action points made by panel speakers and workshop participants. All of the access issues mentioned above were reflected and the theme of how access needs are interrelated arose in several important areas. In the discussions of transportation, for instance, participants called for making public transportation accessible to persons with disabilities to improve their access to a wide range of other important services.

With regard to relationships and family, the participants called for change in attitudes, improvements in the standards and monitoring of institutional care, and investment in support systems for families. Education systems are the catalyst for change in society; therefore education must be inclusive, not divisive. Accessibility requires building capacities through better health and education, microfinance and investment opportunities – there is no field that stands alone.
5.1 Panel presentations

Panel speakers at the conference focused on four aspects of access:

5.1.1 Access to justice
Speaker: Facundo Chavez Penillas, Network for the Rights of People with Disabilities, Argentina

“If people with disabilities are excluded from access to justice, they are also excluded from civil society and democracy. This means that access to justice is a prerequisite to human rights.”
—Facundo Chavez Penillas

Partial, but not full, access to the law: this was Mr. Chavez Penillas’ opinion on access to justice in Argentina. The panel speaker on this topic, he outlined how examining the situation in Argentina provided commentary on many justice systems, in which the rights of people with disabilities are theoretically recognised through legislation, but not borne out in practice.

For instance, NGOs in Argentina have promoted disability rights leading to an increase in the number of legal claims in this area. In response, health services and the government have increased non-compliance with disability laws and poorer people thus have even less opportunity to access justice.

Lack of knowledge of their human rights by people with disabilities, and lack of training in the area of disability among judges and lawyers, was a recurring issue in the Access cluster discussions. This is a bigger problem for people with disabilities than for some other social groups, such as those seeking legal redress around issues of gender, cultural identity and collective rights, because of the relative lack of organization among disabled people. People with disabilities may not see themselves as belonging to the same social group, or may not have reached the stage of organizing themselves to change laws and practices. This is also true of governments, which might not recognize disability as a crosscutting issue, for instance, in the way that gender often is.

Because people with disabilities may not have much money, they are also disadvantaged by the high cost of legal services. Many countries, including Argentina, have only limited free legal services, and private pro bono lawyers are not necessarily sufficiently committed to working on these issues.

In many countries, the legal system supports some rights of access more than others. Mr. Chavez Penillas has analyzed decisions made by the Supreme Court of Argentina in this area, and found that 95% of cases involving access to health care are found in favor of the plaintiff with a disability. This is completely reversed in cases of access to transport, housing and education, where 95% of legal decisions go against the disabled plaintiff.
Reasons for this may include that the health sector is publicly funded in Argentina and so everyone should be able to use it. In other cases, judges may be reluctant to apply disability rights over property rights in the private sector.

The outlook of the Supreme Court is not all negative, however. In response to questions from conference participants, Mr. Chavez Penillas outlined how last year, in elections for the mayor of Buenos Aires, the Supreme Court ruled against accessibility in voting laws. This year however, it declared that if the voting station is not accessible, people with disabilities can choose to vote outside. There is now also a legal framework for disability rights cases being taken to the court. These are all large gains for Argentina's legal system and for people with disabilities.

He also highlighted some of the positive developments in access to justice in Argentina. Law schools there have changed their curricula and created programs on disability. Various stakeholders have also joined together to inform teachers of the law on disability rights, and have formed a disability program for all universities in the country.

Developing this process in universities is not enough, however. In common with his legal colleagues from Sierra Leone and Kenya, Mr. Chavez Penillas calls for training for lawyers, judges and everyone in the legal system in disability rights. This will be crucial to the effective implementation of the UNCRPD, both in countries where there is disability legislation, and in those without it.

5.1.2 Access to ICT: If your neighbor is sitting on the floor, you can’t ask for a chair
Speaker: Dr. Joseph Ngu from UNESCO’s International Institute for Capacity Building

This is the analogy used by Dr. Joseph Ngu to illustrate the difficulty of addressing accessibility of ICT in Africa, where many basic services, such as electricity and clean water, are luxuries for many people. Despite this, his organization recognizes that access to ICT is very important for people with disabilities, and their policy towards ICT is guided by three interrelated concepts: access, quality and equity. In order for ICT to become truly accessible in education, he argues, there are four prerequisites:

1. Access for all students in and out of classrooms
2. Access for teachers and trainee teachers
3. Access for teacher educators
4. Access to researchers in the field of education.

At the moment, Africa is a long way from this goal. A look at the indicators reveals why:

1. Tele-density varies widely across the continent
2. So does the number of computers per school or education system
3. The cost of broadband in West Africa can be prohibitive
4. The brain drain of ICT professionals to other continents is a big problem.
These factors combine to create a situation in which ICT, which could help in providing access in education and many other areas of life, such as work and the legal system, is in itself inaccessible. It may also heighten the disparity between people with adequate incomes and those who live in poverty, which unfortunately includes a large percentage of people with disabilities in Africa.

Participants in Access workshops echoed Dr. Ngu’s call for access to ICT, exploring how access in ICT can also take many forms. Like any machines and media that open up opportunities, care must be taken to ensure that they meet a wide range of access needs. People with visual impairments, for instance, have different access issues than people who have mobility impairments.

These themes tie in with issues of inclusive education, where children with disabilities attend mainstream schools, and require access to learning materials that are the same as those used by other children or equivalent, but adapted to meet their particular learning needs. Dr. Ngu considers student-centered teaching, professional development, community support and changes of policy to be essential to the use of ICT in education. Interestingly, all of these are also considered by conference speakers and participants to be prerequisites to inclusive education as a whole, not just in relation to the use of ICT.

So far in Africa, there has been only limited participation by the private sector in delivering ICT services, and few local producers of digital equipment or resources. There are also few finance mechanisms for mainstreaming ICTs in education and, in some cases, there may be resistance to changing existing teaching systems to include ICT.

This year there will be an inclusive education conference in Geneva to explore some issues around ICT and education. It is important, Dr. Ngu asserts, that we consider obstacles to achieving our goals – plans are easy, but action isn’t. For instance, programs can get computers into schools, but they must also be kept in good condition and teachers must be trained well enough to train their students.

For the future, Dr. Ngu calls for policy development at all levels that boosts the integration of ICT in education. He also believes that organizations and governments should support NEPAD’s education initiative to train teachers and school officials in ICT. On a continental or global scale, it is important to harmonize regulation and include ICT policies in national development frameworks. Beyond this, considering the private sector to be wealth creators with a critical role to play would harness their potential as supporters, donors and sources of accessible ICT for education.


“What we must eliminate first are issues of accessibility – communication and information is very important in our world.” – Maria Verónica Reina, Conference Keynote Speaker, Executive Director of the GPDD.
5.1.3 Access to employment
Speaker: Daniel Mont, Senior Economist, Disability and Development Team, World Bank

In Sub-Saharan Africa, 55-90% of people with disabilities are unemployed, and in every country in the world disabled people have lower employment rates than non-disabled people. These stark figures set the tone of Daniel Mont’s panel speech, in which he explored a range of barriers to work that people with disabilities now face, including:

1. Stigma and prejudice
2. Low expectations
3. Lack of access to education and training
4. Lack of accessible transportation and infrastructure
5. Lack of accessible workplaces and accommodation
6. Structure of disability benefit programs.

It is interesting to note that most of these barriers are not directly related to employment policies. For this reason, addressing access to employment requires a comprehensive and holistic “no-gap” approach.

To offer an idea of how this might be achieved, Dr. Mont first considered disability benefit systems. It is interesting to note that benefits policies are now the most studied elements of disability and employment, which says a lot about how we consider the relationship between disability, benefits and work. Policies in those countries lucky enough to have benefits programs often share several characteristics that act as disincentives to returning to work. These include a fundamental tension between the concept of accepting disability as a limiting factor, and inclusive employment policies, in which the workplace itself may be encouraged to change to accommodate people with different access needs.

People often fear losing benefits, which limits their willingness to try new jobs or training programs that might make it hard for them to regain the benefits they have temporarily relinquished. The application process for benefits frequently requires people to state why they deserve state support and why they cannot work, which probably has a psychological impact on someone’s beliefs about his or her own capabilities. For these and other reasons, exit rates from benefits programs are very low throughout the world.

Several methods have been tried to overcome these problems:

1. Putting benefit eligibility on hold while people start working
2. Temporary wage supplements and tax incentives for people coming into employment after periods on disability benefits
3. Trial work periods that allow people to return to benefits systems if necessary.

Usually, however, these reforms do not work because they do not address other barriers to work, such as access in the workplace, attitudes and transport. Anxiety about the
risk of losing benefits often remains a factor, even if the state tries to deal with these financial fears.

To address the larger issue, Dr. Mont then considered several employment policies. The first was quotas, which in general tend not to be very effective, can be expensive to enforce and usually do not address the informal sector. By themselves, they usually only cover discrimination and not other barriers, which may reinforce the idea that disabled people are not as useful or efficient in the workforce. Also, employers can often avoid them both in practice and in spirit. Vocational training and rehabilitation is another approach to inclusion, and some studies have shown these programs can pay for themselves, although this is not always the case. Unfortunately, comprehensive cost-benefit studies have not yet been undertaken. Supported employment (for instance, using job coaches) is an allied approach, and studies show that this is particularly effective for those with cognitive and psychological disabilities.

Subsidizing wages for people with disabilities can also lower barriers to hiring. There is a danger of a revolving door, however, whereby employers hire people who attract subsidies, and then let them go once the subsidy periods expire. Even these limited periods of employment do provide job experience to disabled people, but, unfortunately, overall subsidies have not been a big success. An alternative approach, subsidizing increased accommodation costs, can be effective once attitudes begin to change.

Dr. Mont argues that there is a strong business case for disability management programs, which have succeeded to date because they have been aimed at people who become disabled on the job. They usually include:

1. Medical and vocational rehabilitation 
2. Workplace accommodation 
3. Counseling 
4. Help with the transition back to work.

The negative here is that this approach usually only applies to people who have recently acquired disabilities. It does, however, give employers experience with accommodating a disabled person.

Another interesting employer-led strategy operates in Sri Lanka, through the Employer’s Federation of Ceylon. To promote employment opportunities for people with disabilities, they:

1. Hold awareness raising seminars 
2. Created a database of disabled people seeking work 
3. Publish a newsletter highlighting good practices 
4. Host job fairs 
5. Provide training and job support 
6. Published a Code of Practice on Managing Disability Issues at the Workplace.
One member of the Employer’s Federation of Ceylon, CEI Plastics, employs 40 people with disabilities, many of whom have visual impairments, out of 300 staff. This amounts to approximately 10% of employees, and their production average is higher while their accident rate is lower. This 10% figure is approximately equivalent to the percentage of people with disabilities worldwide, and thus provides an interesting model of how companies can incorporate disabled people into the global workforce.

The World Bank itself could learn from some of these efforts. While it always states that people with disabilities are welcome to apply for jobs, the number of disabled staff is well below 10%. To help improve this statistic, the World Bank established a disability accommodation fund to cover extra costs required, such as a personal assistant for travel.

As the UNCRPD comes into force, countries around the world can benefit by combining the best existing inclusive employment practices, and developing new ones that address all barriers to work. It is impossible now to say that a particular approach, such as getting people off benefits, doesn’t work, because no approach can work in isolation. As a checklist for how to begin, Dr. Mont offers the following:

1. Take a holistic approach coordinated with other sectors
2. Tailor programs to local labor conditions
3. Introduce different programs to address different segments of the population
4. Gather evidence to make the business case to enlist employer and government support.

Most of all, we must remember that people with disabilities are not a homogenous group. Each person has different needs and all must be addressed for full access to employment to be achieved. The UNCRPD also defines human rights for people with disabilities. In most employment scenarios, taking the rights-based approach will be the best mechanism for bringing about change.

5.1.4 Access to education: from primary to tertiary
Speaker Dr. Elly Macha, Executive Director of the World Blind Union

“Universal Primary Education is not new – it was declared as a goal in 1960. It was restated as a Millennium Development Goal (MDG) in 2000, and what is missing is the process of reaching those goals – inclusive education. We can structure MDG targets in ways that enhance disability rights.”
– Augustine Agu, UNICEF Ethiopia

How to reach these goals, particularly within the framework of Article 24 of the UNCRPD, was the focus of the fourth keynote speaker, Dr. Elly Macha, Executive Director of the World Blind Union. It is well known that in developing countries, approximately 90%
of children with disabilities do not attend school. There are many reasons for this, and efforts to educate disabled children have followed a similar pattern in many countries.

Provision first began within families who educated their children themselves. Children in institutions were then also taught, as these organizations changed from being purely care homes to including education among their services. Some of these then evolved into special schools and then slowly transformed into integrated schools, with several models being followed.

The first model was based on the idea that disabled children would only be integrated with their non-disabled peers outside the classroom or for special events. The more recent approach, inclusive education, turns this around, with the presumption that children with special educational needs should be taught within mainstream schools. In this model, services should be made to accommodate children’s needs rather than children having to accommodate the needs of school settings.
Inclusive education is built around a belief and understanding that education is a basic human right, and the foundation for a just society. The process of making this right a reality – the progressive shift from traditional special educational needs provision to integrated service provision, and then to inclusive education – has created some tensions between and within groups of professionals, researchers and children.

Dr. Macha believes that this is to be expected because educational reform is complex, non-linear and frequently coupled with all sorts of political jargon. It is messy and often threatens the status quo, sometimes hurting people’s feelings in the process. She began with this thought to explain the common understanding of inclusive education and strategies to develop inclusive schools. It is important to make a distinction between:

1. The attempt to determine patterns of inclusive education, and
2. The importance of understanding its contextual framework and philosophy, which could mean that different models work in different situations.

Dr. Macha went on to pose a series of questions to help people understand how inclusive education can be implemented, and accommodate children with disabilities. Overall, the global movement in support of inclusive education focuses on three issues:

1. To what extent is inclusive education guided by an educational vision at a country level?
2. To what extent is the status of the teachers facilitating the bringing about of sustainable inclusive education?
3. How can the inclusive education process be sustained at school level?

In answer to the first question, inclusive education is a vision in itself – an important one for most African and developing countries to consider. To achieve this vision, a country must have a strategy to achieve it.

The second question raises the issue of how prepared teachers are to implement it successfully. If we take the example of Tanzania, where teachers have now resorted to taking additional work, such as running petty cash businesses, subsistence farming and offering extra tuition, because their pay is so low, this gives an indication of how serious the situation can be.

For inclusive education to succeed, we need to get teachers on board, to train them and consider their wellbeing so that they can fully engage in implementing the fundamentals of inclusive education, such as including children with disabilities in their classrooms. The problem of teachers being engaged in other businesses to supplement their small salaries is a barrier to creating this engagement, and must be considered.

From her point of view, for inclusive education to be sustainable, the school community from the head teacher, school staff, school committee and whole local community should be involved in its design and planning. National and local governments also need to allocate resources to it, both human and material. There have been cases where inclusive education programs have been implemented, but have run into
problems because some elements, such as crutches, were not included in the budget. In one country this came to $10 per child annually, but this government could not afford to pay for anything beyond the basics.

In some places, parents of non-disabled pupils also removed their children from the schools, because they believed quality would decline when disabled children joined the classes. Education and attitude change within the whole community, not just families of children with disabilities, is necessary to prevent this kind of problem. To facilitate these necessary changes, Dr. Macha recommended two main directions for action points:

1. **Cooperation between inclusive education stakeholders**

   At the moment, Dr. Macha believes that there is not enough collaboration and cooperation among disabled people’s organizations (DPOs) and NGOs working in education with children with disabilities in Africa. Even in one country, it is common to find several organizations doing similar work in different areas without coordination.

   This has been partly addressed by some campaigns, including one launched in 2006 by the World Blind Union and the International Council for the Education of the Visually Impaired. It is now being put into practice in several Latin American countries, in Asia, and will soon start in Africa.

   UNESCO has endorsed this campaign, but inclusive education is a policy issue, and Dr. Macha proposes that helping it to become reality requires collective lobbying and a common campaign to ensure that all children are enrolled in school. People with different impairments often have their own groups, such as organizations for deaf people. Will they then go to UNESCO and ask to be part of the campaign for blind children? Would it not be better for all DPOs, development agencies and other interested organizations to lobby for inclusive education as a whole?

2. **Early intervention for children with disabilities**

   There are times when service providers and other professionals do not cooperate. For instance, if you go to Kikuyu hospital in Kenya, some ophthalmologists have no idea that a child with visual impairments can be educated in a school, so once a child’s sight cannot be restored, the doctor can offer no advice to the parents. The challenge is for professionals and service providers to be linked, so that we create early intervention programs to identify children for school and inclusion with their peers.

   In 2007, World Vision UK and the GPDD researched the 28 fast track countries (named this way because they were funded by the G8 to support the Millennium Development Goals) and the problems they had in promoting education for all. Dr. Macha recommended that everyone at the conference check if his or her country is a fast track country and,
if so, try to persuade the G8 funded programs there to include children with disabilities in their work. We must remember that we have the resources – all we need now is the will to change.

5.2 Workshops

5.2.1 Inclusive from the start? — Workshop 1: Creating accessible services in post conflict countries
Speakers: Dr. Maria Kett, Assistant Director, Leonard Cheshire Disability and Inclusive Development Centre, University College London
Professor Osman Mohamed Bah, Leonard Cheshire Disability Regional Programme Manager, West Africa
Mohamed S. Kamara, Young Voices Participant, Sierra Leone

“People value mining more than education”
– Survey respondent, Kono, Sierra Leone

The UN rated Sierra Leone, a country ravaged by eleven years of civil war, the poorest in the world in 2007. Its health and education systems have been decimated, and no accurate statistics about disability now exist, nor is there any disability legislation. There are 450,000 children out of school in Sierra Leone, and because of war violence, land mines, measles, polio and other diseases caused by disrupted vaccination services, we know that a number of these children have disabilities.

Even to begin to approach the Millennium Development Goal of universal primary education by 2015, significant rebuilding of the country’s education system will be necessary. This gives the opportunity to make the system inclusive almost from its outset.

Net primary school enrolment from 2002–2005 was 41%, because poverty means both that parents cannot afford school fees and that they need their children to earn money for the family. UNICEF has built many schools with support from communities, and a catch-up education program was launched after the war – CREP or Compulsory Rapid Education Programme.

Professor Bah and Dr. Kett researched the number of disabled children in and out of pre-school in two areas of Sierra Leone: Koinadugu, the second largest and most populated district, and Kono, a poor agricultural and diamond mining area. They found that Koinadugu has only three primary schools and no secondary school, while distances from homes to school are long and the terrain is difficult. The average school fee is equivalent to $10.

Overall in Sierra Leone, 41% of children attend school. 76% of children with disabilities, however, do not attend school.
In Kono, there are 14 secondary schools and six technical institutions, yet the research found that many people value mining more than education. With average school fees totaling $33, many parents and guardians cannot afford to send their children to school. It is thus not surprising that 76% of disabled children do not attend school.

Even if a child with disabilities is in school, there are often problems with access, and this continues at the secondary school level. Mohamed Kamara, whose school is almost completely inaccessible, vividly described this. The school, about two kilometers from his home, has no ramps, and Mohamed and other disabled students have to climb staircases every day. The toilets are located up a hill, without any accessible routes to reach them.

Getting to school is also difficult, because few vehicles are accessible or have space for wheelchairs or other assistive devices. Sometimes drivers even accuse disabled people of wasting their time, meaning that pupils with disabilities spend hours just getting from home to school and back again.

Taking all these factors into account, the workshop called for three main action points to build and rebuild Sierra Leone’s education infrastructure, and make it inclusive from the start:

1. Work with and through the national education system, ministries, international and local partners and NGOs to promote pre-school education
2. Lobby bilateral and multilateral organizations to make reconstruction programs inclusive and development-led
3. Establish and support networks of pro-disability and disability organizations to advocate and campaign for inclusive development policies.
5.2.2 ICT: creating division or creating opportunities? – Workshop 2: Reducing the digital divide and the role of ICT

Speakers: Jenifer Simpson, Senior Director, American Association of People with Disabilities, USA
Dr. K.M. Baharul Islam, Chairman and CEO, South Asian Regional Development Gateway, India

Information and Communications Technology (ICT) has the potential both to enhance access for disabled people and to contribute to creating more division and new forms of exclusion. It is thus vital that issues of access be addressed, as technology continues to develop and spread.

What we now call the digital divide actually began long before the introduction of computers – it is true today for telephones, television, the Internet and electronic help systems. It is important to remember both that people have many different access needs, and that there are many different ways to make technology accessible. For instance, telephones can be accessible through their keypads, through using a telephone relay operator and by making phone devices work with hearing aids. In the USA, it took over ten years of lobbying to convince manufacturers to make television accessible, and this had to focus on both TV sets themselves and the provision of closed captioning and video description, which remains a voluntary access service. Controls, instruction leaflets, and electronic program guides, for example, are still targets for accessibility lobbying.

Sometimes, the technology itself develops to a point where it is more accessible. For instance, the increased use of broadband could prove to be an effective boost for accessibility, as it is quicker and can carry videos and other media. To make this work however, disability access must be designed into sites from their outset. Computer manufacturers must also ensure that software works for people with all disabilities.

Internationally and regionally, there are a number of accessibility initiatives. The largest is the declaration of principles developed by the World Summit on Information Technology (WSIS), a series of two international meetings sponsored by the International Telecommunications Union, the UN and the governments of Switzerland and Tunisia. Its conclusion is that those in the “information society” should pay particular attention to the special needs of persons with disabilities in all stages of education, training and human resources development, including infrastructure. The WSIS meeting also advocated universal design concepts and the use of assistive technologies to support persons with disabilities.31

In Asia, UNESCAP helped create “Recommendations on Policy/Legislative Guidelines concerning ICT accessibility for Persons with Disabilities in the Asian and Pacific

31 www.itu.int/WSIS
Region, June 2002,” which provides a framework for governments to make ICT accessible in their countries. Each European Union country has individual laws on accessibility, and handles ICT issues through several government departments – no country has a unified system or policy.

In Africa, UNECA has sponsored the National Information and Communication Infrastructure (NICI). Each African country can use this to formulate policies and strategies for using ICT, to create an enabling environment for innovation and to fight poverty. Since ICT penetration in Africa is so much lower than in other continents, there is an opportunity for African countries and companies to build accessibility in at the beginning. Setting aside money and technological assistance to support the use of assistive devices, which can be costly, is a good example of how this could work. To take advantage of all opportunities to make ICT accessible, the workshop called for programs to:

1. Make ICT available at a cost that is affordable for people with disabilities. Such technology exists, but needs to be made widely available
2. Make ICT policy inclusive from the outset. It needs to be mainstreamed to include people with disabilities
3. Make ICT companies pay for making ICT services widely available and accessible. It is good business for them and this approach has worked in the US.

5.2.3 **Inaccessible transport is a barrier to more than travel — Workshop 3: Creating accessible transport where there is little state-funded transport**

Speakers: K. R. Rajendra, South Asia Regional Programme Manager, Leonard Cheshire Disability
Facundo Chávez Penillas, Network for Rights of People with Disabilities, Argentina

Despite living on different sides of the world, people with disabilities in India and Argentina have something in common: in both countries most public transport is inaccessible. This is not only an inconvenience, but also a direct barrier to accessing other services, such as health care and education.

In India, where 70% of the population lives in rural areas, roads are often in poor condition, and structures such as bus shelters and train stations are often inaccessible. The Leonard Cheshire Disability South Asia Regional Office carried out a study on transport accessibility for Mobility & Health – a networked research program of IFRTD, the International Forum for Rural Transport and Development. Examining whether and

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32  www.dinf.ne.jp/doc/english/asia/resource/z00ap/vol5no2/recommend.htm - 22k
33  www.uneca.org
how people with disabilities can travel to their nearest primary health centre, which ranged from one to 24 kilometers away, it found that:

1. Roads were paved with asphalt, but they were narrow, potholed and had no pavements/curbs
2. The distance from a village to a main road that could take someone to a primary health center averaged one-half to one kilometer
3. Most people had to hire private transport – such as cars, rickshaws or jeeps
4. Most transport options ended by 10 p.m., sometimes as early as 6 p.m., making it difficult for people in emergencies
5. There were no directions or signs on roads or in bus shelters, so people with visual or hearing impairments, intellectual disabilities and mental illness might need an escort to guide them
6. There were no facilities for communication with people with hearing and speech impairments, and no announcements on buses for those with visual impairments.

When people could take a bus, drivers were found to be helpful, but often people with disabilities would choose not to board a crowded vehicle because they would be jostled. And, although the first few rows of a bus are reserved for people with disabilities, non-foldable wheelchairs and mobility tricycles don't fit on buses.

Given these issues and the facts that 99 out of 100 disabled study respondents depended on public transport and only one owned a vehicle, it is no surprise that people with disabilities rarely visited health centers. The implications for their health are, obviously, serious.

In Argentina since 1981, the Argentinean Accessibility Law (AAL) has covered physical accessibility. The capital city, Buenos Aires, approved its own accessibility law (ALCBA) in 2003, largely as a result of lobbying by disability and other organizations working together. Five years later, ALCBA has been included within the city’s Buildings Code, which should make new structures more accessible.

Yet enforcement is far from being effective. For example, over 75% of public and over 80% of private schools are inaccessible in Buenos Aires, the richest jurisdiction in the country. Among the students with disabilities who would be entitled and able to attend these schools, 82% cannot attend and are excluded from the educational system because of inaccessibility.\(^{34}\)

Should students be able to find an accessible school building, they would have significant trouble getting there. Although AAL covers transport accessibility, political lobbying of congressmen by the transport industry meant that it was not applied for over 15 years. In 1998, the first accessible buses appeared in Buenos Aires. After ten years, less than

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\(^{34}\) Fundación Acceso Ya, 2006 and Auditoría General de la Ciudad de Buenos Aires, 2004
20 of the 199 city bus lines have fleets in which over half of the vehicles comply with accessibility rules. Most of these serve only wealthy areas of the city.\textsuperscript{35}

Participants in this workshop recognized that making public transport accessible involves a web of legal and practical changes. The benefits will increase access to a broad range of activities, making transport fundamental for full participation in society. To best make this happen, they called for concerned people and groups to:

1. Work in partnership with governments, not against them, in organizing budget allocations and policies for people with disabilities
2. Work with the media and governments to develop a program of training and awareness to sensitize local communities on the need for accessibility
3. Develop a policy on accessibility, not only in terms of one single element, but also as an over-arching program for transport accessibility in an area or country. This includes all elements of transport, including information in accessible formats and other issues not directly related to vehicles.

5.2.4 Support children with disabilities by supporting families — Workshop 4: Access to relationships and family life
Speaker: Helen Schulte, Child Protection Section, UNICEF, USA

Children with disabilities are entitled to live in families, not institutions. This right is detailed in articles 19 and 23 of the UNCRPD, which calls for governments to support it through information and services.

Around the world, however, at least two million children live in institutions, and the number is growing, especially in Africa because of the impact of HIV/AIDS. This workshop explored how in Central and Eastern Europe and the Russian Federation, a disabled child is 17 times more likely than a non-disabled child to be institutionalized.\textsuperscript{36} Sadly, the majority of children in institutions do have at least one living parent. There are many reasons why children may end up in institutions, including:

1. Economic pressures (costs of raising a child with a disability)
2. Lack of services and support in the community
3. The social stigma and discrimination families and children face
4. Professionals who insist that institutions provide the most effective care.

In Eastern Europe, the social benefits system almost incentivizes institutional care, as this mother’s comment shows:

\textsuperscript{35} Dictamen 114/2004 of INADI (anti-discrimination public institute) on accessibility of public transporta-

\textsuperscript{36} ‘The right of children with disabilities to family life: Preventing separation and promoting family sup-
If a child is in a boarding school, then the state pays 150 lats (240 Euros) for a child per month. How can it be compared [to what we receive]? If a child grows up in a family, the only money the family receives is 35 lats (56 Euros) in disability allowance.\textsuperscript{37}

When separation from the immediate family is unavoidable, alternatives to institutional care include:

1. Foster care for children with disabilities, preferably in other families within the community or family-like group homes
2. Supporting and monitoring informal care arrangements
3. Minimum standards and oversight in the formal care system.

In some countries, such as India, families of children with disabilities may receive no state support. In this context, institutional care may seem to be a positive development.

Helen Schulte agreed that there is still a role for institutional care, but believes that governments do need to change policies and incentives. Investing in supporting families rather than institutions would help. Standards of monitoring of institutional care also need to be improved.

Effective strategies to avoid institutional care by societies, governments and stakeholders can increase the percentage of children with disabilities who live in families. These include:

1. Increase attention to children with disabilities in social protection reform processes
2. Invest in family support services that are accessible to children with disabilities and their families
3. Strengthen the state’s social welfare sector
4. Provide day care services so that both children and families have support during the day
5. Improve early assessment and intervention so that disabilities can be identified early, and children can receive the appropriate support.

Workshop participants illustrated the very wide range of approaches to community support internationally.

In South Africa, there are programs to empower mothers to support each other financially, materially and emotionally. They have also formed lobbying and campaigning networks.

The Khartoum, Sudan, Cheshire Home looks at developmental systems, with a focus on families, children and community-based rehabilitation that helps integrate a child with disabilities into the community.

\textsuperscript{37} As above
The **Cheshire Home in Guyana** has four to five applications a week for residential care for children, far more than it can handle. Families are requested to keep in touch with children who live in the home, but many do not. There seems to be a high level of disabled child or family abandonment in Guyana and other countries, particularly fathers abandoning mothers and children.

Representatives from **China** report similar issues, but families that have more resources than the birth parents are increasingly fostering children with disabilities. International adoption of children with disabilities is another trend.

Participants from every country represented agreed that changing attitudes must be part of any effort to ensure children's right to family life. Together they called for the following action points:

1. Improve standards of monitoring of institutional care, while at the same time focusing on investing in support systems for families
2. Early intervention, assessment and support are necessary to identify disabilities at an earlier age
3. Men must be accountable for their disabled children
4. Change the attitudes of the wider community to avoid stigmatization of disabled children
5. Build capacity and educate donors to move away from investing in institutional care and into support for families.

### 5.2.5 Meeting the most basic needs: Access to water and sanitation — Workshop 5: Making public buildings accessible: examples of good practice in water and sanitation

Dabashish Bhattacharjee, Human Settlements Officer, UN Habitat, Kenya  
Mahider Tesfu, Research Officer, WaterAid Ethiopia

UN Habitat has already produced principles for accessibility of public buildings that have been endorsed by the world's governments. One important point is to promote access for all people to safe drinking water, sanitation and other basic services, facilities and amenities. This is to be achieved by promoting the adoption of laws, standards, planning guidelines and programs that consider specific needs of persons with disabilities, including people who are chronically ill.38

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38 “Access to Water and Sanitation for the Disabled or the Differently Abled,” Presentation by Andre Dzikus, Chief, Water, Sanitation and Infrastructure Branch, Section II, and Debashish Bhattacharjee, Human Settlements Officer, Water, Sanitation and Infrastructure Branch, Section II, 22 May 2008, Addis Ababa, Ethiopia
These ideas are echoed in Article 28 of the UNCRPD and should be implicit in the Millennium Development Goals, which cannot be met without the inclusion of people with disabilities. A number of issues hold true in many countries:

1. Disabled people often have the poorest access to water and sanitation, because of physical barriers such as steps and inappropriate design, as well as attitudinal barriers that keep them away from public facilities for personal or social reasons.

2. Inclusive facilities benefit the entire community:
   - Burden on care givers (mainly women) is reduced
   - When people with disabilities get water-related infections, their families and communities become at risk, which also impacts on the local economy
   - Inclusive facilities are economically more efficient – “specially” created facilities are expensive

3. Disability, poor access to water and sanitation and poverty are interrelated, for instance, polio and water contamination by fluoride and arsenic all cause disability

4. Diarrhea, which is often caused by lack of access to clean water, is responsible for 5% of health loss from disability

5. People with disabilities may need more water for washing because of their disability – for instance, some people may crawl or fall frequently

6. Official statistics often underestimate the proportion of persons with disabilities

7. Programs that provide public water and sanitation facilities often do not consider the range of users trying to access services

8. Development organizations may overlook people with disabilities in their water and sanitation projects, while disability organizations rarely address water and sanitation issues.

Combating all of these requires integrated approaches, particularly focusing on the participation of people with disabilities, attitudinal changes and user-friendly water and sanitation services. WaterAid in Nepal has created “Guiding Principles for Planning and Design”.

**Accessibility:** Water and sanitation facilities should be accessible to all people, including those with disabilities, elderly people, pregnant women, and children; consider limitations faced by differently abled people (discomfort, fear of falling).

**Access:** Persons with disabilities should be able to access without assistance and without undue difficulty; barriers in the natural environment, like slippery slopes, and cultural practice of locating latrines far from the house, should be considered.

**Usability:** Everyone should be able to use facilities (this has impact on the height of taps, use of platforms, etc.).

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Small adjustments can help a lot:

- Two wooden guide poles can help a blind person access a well
- A wooden stool with a hole in it can help children sit on a latrine
- Handrails help people transfer from a wheelchair to a latrine
- Concrete ramps from houses to latrines help with wheelchair access.

**Safety**: Facilities to be built in a way that does not endanger life or health – consider hand rails, rough surface finishing, alarms.

To address all of these issues, WaterAid and UN Habitat call for:
1. Participation of PWDs in programming and policy advocacy work
2. Inclusive design of water and sanitation facilities
3. Integration of access to water and sanitation into policy advocacy work
4. Media work to tackle misguided beliefs
5. Production of policy brief and issues papers
6. Collaboration between development and disability organizations
7. Improved data collection and further research, including piloting inclusive designs in study areas and changing practice as a result of findings.

### 5.2.6 Making universities catalysts for change — Workshop 6: Higher education and inclusion

Speakers: Dr. Windyz Ferreira, Leonard Cheshire Disability, Brazil
Dr. Abdul Hameed, Chairman, Department of Special Education, University of Punjab, Pakistan

Higher education can act as a catalyst for change. Working within universities gives an important opportunity to promote the rights, skills and access of disabled people in higher education and the wider society. But, while the total number of university students in the world rose from 13 million in 1960 to 82 million in 1995, the large differences in access to universities between industrial and developing countries became even wider.40

People with disabilities can face many barriers to full access to a university education, says Dr. Windyz Ferreira, based on her research into disabled students’ experiences in Brazil and other countries. Starting at school level, these can include lack of access to a quality education, “invisibility” in everyday settings, lack of understanding of diversity issues, and a limited number of places at universities. Once they reach university, barriers can include academics who are unwilling to adapt teaching methods for people with disabilities, problems with physical accessibility and a lack of trained professionals to support students with disabilities.

Since 2000, the University of the Punjab in Pakistan has taken specific steps to help overcome these barriers:

1. Ninety seats (2% of the total) were created in all programs for students with disabilities
2. About 50 students with disabilities are admitted on merit every year

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40 The World Declaration on Higher Education, UNESCO 1998, page 1
3. There is a special admissions committee for determining eligibility
4. There is flexibility in curriculum, instruction and the system of examination
5. Support is given to faculty members to accommodate disabilities.

The Department of Special Education plays a leading role in this program through advocacy for inclusion, teacher preparation, research on inclusion, support to inclusive institutions, learning resource center on inclusion, promoting innovation in education, national and international collaboration, and putting theory into practice.

Within their own department, they decided to shift from “reserved seats” to full inclusion. As a result of advocacy, six people with disabilities applied for admission to the MA course in special education in 2004, compared to one reserved seat. The university then agreed to create five seats (about 10% of the total), meaning that five disabled students are admitted each year. The master’s program set out to create an inclusive environment, and changed the classroom culture from social exclusion to social inclusion. Methods for doing this included:

1. Changes in class arrangement and space allocation
2. Modification in physical facilities
3. Improvements in social environment
4. Flexibility in instruction and note taking
5. Flexibility in examination
6. Changes in social environment
7. Flexibility in performance criteria.

At the university, they strongly believe that creating an inclusive education system at the primary and secondary levels is necessary, before there can be truly inclusive tertiary education. Empowerment of people with disabilities, both inside and outside of education, is also necessary to make this happen.

The workshop participants agreed on six calls for action to make higher education more inclusive:

1. Encourage UNESCO to hold an international conference on inclusive education and innovative learning, to exchange experiences and ideas
2. Create an online network (possibly initiated by the Leonard Cheshire Disability and Inclusive Development Centre at University College London), where ideas can be exchanged
3. Create a conceptual paper in easy language about moving away from the medical model towards the social model. Include “curriculum differentiation” – teaching the same curriculum in different ways
4. Start a debate on innovative teaching processes

The University of Mauritius worked with disabled people’s organizations in the community to raise awareness of university access for students with disabilities.

In Ethiopia, students organized themselves to campaign for construction of a ramp to the library, which had previously been inaccessible.
5. Lobby ministries of education to create policies and practices that prepare students in secondary education for higher education, and those in higher education for jobs.

6. It is essential to have a university that will act as a focal point to support and fight for the rights of students with disabilities. Students must be empowered to fight for their own rights – it is not always a question of government policy.

5.2.7 Building disabled entrepreneurs — Workshop 7: Poverty and indebtedness among people with disabilities - is microcredit an effective answer or cause of further debt?

Speakers: Alvin Uronu, Institute of Continuing Cooperative Development and Education, Tanzania
Roy Mersland, Director, Microfinance, Norway

Yes and no, depending on the circumstances: this was the opinion of the workshop after considering two different microfinance programs in Africa. Local market conditions, participants’ previous work experience and skill levels all influenced whether microfinance would be effective in supporting small businesses.

Alvin Uronu, who works with Moshi University College of Cooperative and Business Studies (MUCCoBS), one of Leonard Cheshire Disability’s project partners, examined a livelihoods support project in Dodoma, a central area of Tanzania approximately 450kms from Dar es Salaam. Most people live on less than $1 a day and there are few non-farming activities. The area’s semi-arid climate and low soil fertility mean that food security is always an issue.

The project targets people with disabilities, and parents or guardians of children with disabilities. Project participants meet once a week in one of six centers located within their communities for training, and to access financial services such as savings groups. Designed to combine provision of microcredit and training in entrepreneurship skills, the project builds capacity to stimulate new microenterprises, create employment, and develop confidence and good practice in financial management.

Of the 356 participants, 284 are women, and trading accounts for 91.8% of the businesses, with the remainder being in manufacturing and services. The minimum amount loaned is Tshs 50,000 ($50), while the maximum is Tshs 300,000 ($300). The average loan repayment rate is 95%, and participants are also required to save within the group.

A number of participants benefited from the program by being able to increase their business stock. Some were also able to change from mobile to small, fixed businesses. Increases in sales also improved people’s ability to support disabled relatives and other family members with basic necessities such as food, medical services and clothes.
On the other hand, the loans offered are mainly for working capital and are too small to facilitate the purchase of larger tools or equipment. These might include small oil processing machines, weaving machines, sewing machines, or inputs for gardening. Participants are required to start repayment in the week following loan disbursement, and this effectively means that they will remain small traders rather than larger scale producers. This outcome is common in similar projects across Africa, and it can be argued that this type of program does not pull people out of poverty.

It is also interesting to note that people with different kinds of disabilities experience the project differently. For example, people with visual impairments tended to work in crafts, such as weaving carpets, and argued that they could not make weekly loan repayments since it might take more than a week to complete and sell a piece of work. People with motor impairments sometimes rely on their children or other partners to buy or transport raw materials, so it might be worthwhile to build support for this kind of partnership, and possible additional expense, into future programs.

To help people start and expand different kinds of businesses beyond the level of small traders, Mr. Uronu proposed that the community centers could become business incubation centers. These would train people in specific business skills and topics, share case studies, document practices and act as centers of marketing information expertise. They could also help make links between relevant organizations, and even generate publicity.

Roy Mersland, the second presenter, reported that mainstream microfinance institutions (MFIs) often excluded people with disabilities\textsuperscript{41}, since their aim is to remain financially solvent, and they erroneously consider people with disabilities to be bad credit risks. They thus fail to practice the “double bottom line policy” common to many MFIs: reaching both financial and social objectives.\textsuperscript{42}

Mr. Mersland then discussed how an innovative partnership has overcome this problem. Starting in July 2005, Ugandan MFIs and disabled people’s organizations, and their partner the Norwegian Association of the Disabled, set out to increase the outreach of sustainable mainstream microfinance services to persons with disabilities in Uganda. Their two main strategies were:

1. To increase awareness among MFIs about how to include persons with disabilities in their services, and
2. To create awareness among persons with disabilities and their organizations about the pros and cons of microfinance.

The program trained staff in 49 MFI offices in how to approach and work with people with disabilities. No special financial products were developed for disabled people; the focus was, instead, on supporting organizations to market their program to qualifying people with disabilities. They also improved both the physical accessibility

\textsuperscript{41} Handicap International, 2006; Mersland 2005  
\textsuperscript{42} United Nations, 2006; Helms, 2006
of their premises and the accessibility of information for people with visual and hearing impairments.

The DPO partners took responsibility for helping people overcome other barriers to participation such as negative attitudes towards mainstream MFIs or low self-esteem. In 2006 and 2007 the project workshops trained a total of 1,603 people, of whom a third were not actively involved in businesses. They also invested in advertising the project through radio – generating 700 minutes of coverage – and TV talk shows – generating 90 minutes of coverage – during 2006 and 2007. Lobbying with government and industry officials was another tactic.

Preliminary results after 18 months show that before the sensitization, 6.5 out of 1,000 MFI clients had disabilities. After the sensitization, 10 out of 1,000 new clients have disabilities, representing almost a 50% increase, approximately half from natural growth and half as a result of the program. It is interesting to note that different branches had very different rates of increase in participation by disabled people – from 57% to 350% – probably indicating that local efforts can influence the results considerably. The cost of the program has been low in relation to its growth, with staff costs being almost the only increased expense.

Mr. Mersland concluded that, for the time being, aiming for 3% of an MFI’s clients to be people with disabilities seems realistic, and would mean an enormous step forward in mainstreaming entrepreneurial persons with disabilities into MFIs. A 3% natural market potential for MFIs should also be enough for it to be considered an important market opportunity for them. However, the 3% also sends a message to the disability community that more than two thirds of the world’s disabled population is not an immediate target for mainstream microfinance services.

Sustainable MFIs struggle with reaching the poorest strata of the population, disabled or non-disabled. On this point Mr. Mersland agreed with Mr. Uronu: for people with disabilities who are less entrepreneurial, poorer or have impairments that cause them to need more support, other intervention efforts are needed.43

Following a lively discussion of the important issues raised in these presentations, the workshop called for three action points:

In Uganda, more than 60% of the project participants have a physical disability, while the rest have a mental impairment, are blind or deaf, or are caregivers.

“For a loan group to meet and talk only about loan repayment is more than a missed opportunity: it is a failure to grasp what development is actually about. These groups could be the kernel of a consciousness in the community.” Peter Coleridge (2007) Field Report Document for Leonard Cheshire Disability, quoted by Alvin Uronu in ‘The case of Dodoma Micro Finance Project for PWDS’ in Tanzania”, May 2008.


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1. Encourage disabled people’s organizations to promote microfinance to their membership, and to sustain the idea of people with disabilities as an untapped market for financial service providers
2. Promote savings as a precondition to requests for loans and as a coping mechanism for crisis situations
3. Promote further research into the possibility of more flexible conditions for microcredit provided to vulnerable groups.

5.2.8 Independent living is worth the risks — Workshop 8: Moving investment from institutions into accessible communities
Speakers: Gordon Kyle, Director of Social Policy and Government Relations, Community Living, Ontario, Canada
Maurice Kilduff, Executive Director, Cheshire Home South Africa

“For me, independent living is being able to live without being dependent on either state or welfare... it is taking charge of my own daily life. Talking from the perspective of someone who has lived a life of dependence, it is difficult to express the confidence lift that independent living gives to an individual with disability. The experience changes one so much that it is easy to learn new lifestyle skills almost without effort.”
— Mandla Mhlanga, Cheshire Home South Africa Service User

In his paper on independent living, Mandla Mhlanga, a service user from the Cheshire Home South Africa, articulated the longing for independence that he has encountered among many people with disabilities. At the workshop, his representative from South Africa, Maurice Kilduff, outlined the series of steps that Mr. Mhlanga believes are needed for disabled people to make the transition from institutions to community living. Workshop participants then compared these to the approach advocated by Community Living Ontario, a community-based organization in Canada.

Both countries began their services for people with disabilities following institutionally based models, and both organizations then moved in the direction of supporting community living. Mr. Mhlanga believes that the path towards independent living requires a combination of services and changes of attitude among people with disabilities themselves. The first step is to want to be independent and the second is to work cooperatively with others to build a support system based on family members, community organizations and mentors.

This echoes the situation in Canada, where Community Living Ontario promotes a program of family support, individualized planning and community development that supports people with disabilities to live in a range of community settings. According to Gordon Kyle, northern countries previously made the costly mistake of institutionalizing
disabled people. In Africa, countries with less developed social welfare systems now have the opportunity to take the approach that countries such as Canada have adopted, which is to create webs of support and service provision that meet people’s individual needs.

Access to employment was the third of Mr. Mhlanga’s steps, both to become economically independent and to be considered of equal status to other people. “Economics finally rules opportunity. So, if disabled persons seek independence, they must overcome financial difficulties and a host of other hurdles,” says Mr. Mhlanga. This situation is significantly different to that of Canada, which has a comprehensive welfare benefits system, but is common in many lower income countries.

Both in Canada and South Africa, inclusive education has been identified as an important step towards promoting inclusive societies. The same goes for programs that teach living skills and negotiating inaccessible transport systems, which are unfortunately necessary in many countries.

Workshop participants agreed with Mr. Mhlanga that “independent living is worth all of its inherent challenges and all of the frustrations. These are compensated by the joy of living your own life.” To support independent living, the workshop called for three actions:

1. Social workers need to follow up people with disabilities in transition to community care, and be accountable both to the people and to their communities

2. Ensure that people are provided with a full range of options with respect to the support and services they receive to live in and take part in all elements of the community, in recognition of and in response to the person’s particular needs and personal goals

3. Consistent with articles 1, 2 and 3 of the UNCRPD, specific investments are needed to ensure that people with disabilities have support where necessary, to exercise their legal capacity, make informed decisions and engage in community life.

5.2.9 Improving education through inclusion – Workshop 9: Inclusive education

Speakers: Orpa Orgot, Global Education Advisor, Leonard Cheshire Disability
Chris Berry, Education Adviser, DFID Ethiopia and Workyle Tegegn, Embassy of Finland, Ethiopia

The UN Convention on the Rights of the Child, the Millennium Development Goals, and now the UNCRPD, all stipulate that education is a human right for all children. Yet there are still over 70 million children out of school worldwide and about one third of these
are children with disabilities. The World Health Organization states that overall, only approximately 10% of children with disabilities in low-income countries now access education. Why are so many disabled children out of school?

This workshop explored the best ways to include disabled children in mainstream schools, a process known as inclusive education, which allows all children to learn in their local schools.

Orpa Orgot spoke about the successful inclusive education project in Oriang, Western Kenya, run by Leonard Cheshire Disability and several project partners. Before the project began, there were few disabled children attending local schools, and a background assessment revealed that teachers lacked the skills to support children with special needs, school buildings and grounds were not accessible, and learning materials were inadequate. The study also found hostility towards educating children with disabilities from some community members. The project then took a holistic approach to:

1. Enhance teachers’ skills to support them in teaching disabled children
2. Identify out-of-school children with disabilities in the community and help them become role models for other children
3. Build community participation to adapt schools and support children
4. Influence government policy and create a partnership with a teacher training institution
5. Gain support from special education practitioners
6. Network with government departments and NGOs to build partnerships.

44 World Vision, 2006
The active participation of people with disabilities in mainstream education acts as a catalyst for schools and communities to increase disabled children’s access to mainstream schools. To support this, five disabled people actively participate in project management and three disabled teachers support child-to-child education activities in schools and the community. People with disabilities helped coordinate activities in the project’s community resource centre.

The program has been so successful that the original pilot project in five schools has now scaled up to cover all of the 434 schools in the Nyanza province. The participating teacher-training institute has also changed its curriculum to reflect this inclusive approach.

Across the border in Ethiopia, there has been a dramatic increase in the number of children in primary education – from five million in school in 2000 to 14 million now. There have been problems, however, and these include high drop out rates, low completion rates and low levels of attainment.

To improve the quality of education for all students and mainstream crosscutting issues, the government of Ethiopia developed the General Education Quality Improvement Package – GEQIP. This government-led, donor-supported program improves educational outcomes by:

1. Improving curriculum and textbook quality, relevance and availability
2. Reforming assessment practices
3. Teacher Development (in-service and pre-service training of teachers, training of teacher educators, etc.)
4. Training in education management at all levels
5. Empowering schools to plan and manage their own resources.

Disability is specifically addressed through:

**Curriculum, textbooks and assessment:** The curriculum and textbooks are developed in ways that make teaching and learning more inclusive, and the project supplements this by providing adaptive and supportive material. There is also a focus on early assessment in basic reading and writing, to identify children with learning difficulties.

**Teacher development:** Selected teachers are trained in special education needs, to act as resource persons for other teachers and school administrators. The program also provides additional materials to teacher education institutes and cluster centers for teacher development. This has helped scale up teacher training to tackle regional inequities.

45 Susie Miles et al, 2001
**Management and administration:** Issues of inclusive and special needs education have been incorporated into leadership and management training, the budgeting and resource allocation process and the education management information system.

**School improvement:** The program organizes different forums to help increase the awareness level of the school community and parents. We also involve PTAs on activities related to inclusion and special needs education, as well as using school grants to improve the school environment and create different support systems.

The program has generated a lot of interest, but more work needs to be done to refine its impact. The key questions are how to balance expansion with a focus on quality and inclusion, how to support schools to teach special needs children, and how to redesign textbooks to promote greater inclusion.

Through lively discussion, workshop participants generated the following calls for action:

1. Integration – meaning children studying in the same schools but not together – is not inclusion. Inclusion needs a change in attitudes, curriculum, teacher training, assessment, resources and materials
2. It also needs a child-friendly approach, as put forward in UNESCO handbooks and child-to-child training approaches
3. For children with visual impairments and deaf blind children, teachers need to be able to support education in Braille, and be trained to meet other needs they might have
4. Governments, the donor community, local communities and other resource and fund providers, need to adapt their approaches in line with the UNCRPD. Inclusive education needs the support of all stakeholders.

**5.2.10 Health care equity is a development issue — Workshop 10: Access to health care**

Speakers: Dr Hasheem Mannan, Centre for Global Health and National Institute for Intellectual Disability, Trinity College Dublin, Ireland
Ashley Pardy, doctoral student, Griffith University, Australia

Recognizing that achieving the Millennium Development Goals depend on people with disabilities having access to health care, Hasheem Mannan spoke of the work of EquitAble, a consortium of disability and development researchers. Led by Trinity College Dublin and funded by the European Commission, their research focuses on enabling universal and equitable access to health care for vulnerable people, including people with disabilities, in resource-poor settings in Africa.47

Around 20% of children remain out of school in Ethiopia, rising to 70% in some regions — many of these children are likely to have a special educational needs. Kenya’s introduction of free primary education in 2003 supported children with disabilities to access schools.

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47 The EquitAble consortium includes: Afhad University for Women (Sudan), University of Malawi Centre
The European Parliament has recognized the importance of these issues in its “Resolution on Disability and Development 2006.” Article 9 states that each program should “include disability components in its health policies and programmes” and Article 10 includes a call to “promote disabled people’s ...equal access to all health services and programmes.” Article 12 articulates the need to “integrate community based rehabilitation programmes into the primary health care sector.”

In practice in developing countries, however, there are many variations in how health care is delivered. Just a few of the issues EquitAble addresses include:

1. Sudan: a large proportion of the population has been displaced
2. South Africa: despite relative wealth, universal and equitable access to health care has yet to be attained
3. Malawi: chronic poverty and a high disease burden compete for meager resources
4. Namibia: the population is highly dispersed.

EquitAble considers disability to be represented along a continuum of activity limitations, which allows them to identify and monitor specific barriers and ways that these can overcome. It is also important to explore how activity limitations interact with other factors, such as age, gender and ethnicity, in accessing health care systems.

The expected outcomes of the research will be policy recommendations and guidelines at international, regional and national levels. These include practical guidelines in increasing good practice and decreasing barriers to fair and universal access to health care systems. Increasing the research capacity of people with disabilities who participate in surveys will be an additional benefit.

The workshop concluded that:

1. Future policies in health care should all be inclusive and take mental health and disability issues into consideration
2. All stakeholders, including traditional leaders, religious leaders, governments, people with disabilities and civil society organizations, should be involved in ensuring that disability is included in access to primary health care provision
3. People with disabilities should be involved in research, policy formulation, service provision, advocacy, and continuous monitoring and evaluation
4. There should be a disability component in all government ministries realizing that disability is a cross-cutting issue
5. There is a need to advocate for the right to health, including people with disabilities

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for Social Research (Malawi), Human Sciences Research Council (South Africa), Secretariat of the African Decade for Persons with Disabilities (South Africa), The Foundation for Scientific and Industrial Research at the Norwegian Institute of Technology (SINTEF) (Norway), University of Stellenbosch Department of Psychology and the Centre for Rehabilitation Studies (South Africa), University of Namibia Multidisciplinary Research and Consultancy Centre (Namibia).
6. Need for fair and just allocation of resources towards enabling universal access to health care
7. There should be a mid-level cadre of health care providers who are competent in issues of disability.

5.2.11 Equality of access leads to equality under the law — Workshop 11: Access to justice: Sierra Leone case studies

Speakers: Julius Cuffie, Barrister and Solicitor, High Court of Sierra Leone
Pearl Gottschalk, The International Foundation for Disabled Orphans, Sierra Leone and USA

“The virtue, which results in each person receiving his due…”

If we take the above as a working definition of justice, then there have been many international efforts to bring it to life for people with disabilities: the Universal Declaration of Human Rights in 1948; the Declaration on the Rights of Disabled Persons in 1975; and Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993. The UNCRPD is the most recent and the one that has the potential to have the largest impact on legislation and practice in many countries.

Disability in Sierra Leone is a complicated issue because of the violent civil war that ended in 2002, and may offer particular challenges under the UNCRPD’s legal provisions. The war injured both soldiers and civilians, and also disrupted the health care and vaccination systems, leading to disability even among those not directly involved in the fighting.

Since the war ended, there have been many mechanisms to bring about justice for those involved. These include the Special Court, the Truth and Reconciliation Commission, and processes aimed purely at laying the foundation for peace through the Demobilization, Disarmament and Reintegration process, as well as the Lomé Peace Accord process and the electoral processes of 2002 and 2007.

Pearl Gottschalk researched the situation for people with disabilities in 2007, and her findings suggest that the peace processes presented some unforeseen difficulties for persons disabled by war in Sierra Leone. These included international aid to combatants, but a lack of support for people disabled directly or indirectly through the fighting. Many disabled people felt let down by the truth and reconciliation process, saying that participating in the Commission and the Special Court brought physical risks

and fear of retribution. They were also skeptical of its benefits, and sometimes felt that their programs were handed down by foreigners, rather than reflecting local ways of bringing about justice.

Having faced some disappointment in the processes outlined above, in Sierra Leone now, people with disabilities need to rely on the country’s constitution to address their rights. There are several provisions that do this, mostly focusing on preventing discrimination. The practical barriers to enforcement of these laws include:

1. Supreme court proceedings are very expensive
2. The absence of “Equality of Arms” (this may be translated as not having a reasonable opportunity to present a case in court, under conditions that do not place a person in substantial disadvantages vis-à-vis his opponent)
3. Equal legal capacity and equal access is non-existent
4. Some access to legal help may be more cosmetic than actual.

Several measures could help overcome these problems including the creation of a Disability Rights Commission and ratifying and implementing the UNCRPD. From this, the government could formulate an overarching policy on disability issues.

The workshop acknowledged that making the UNCRPD operational will be costly. Participants further believed that to make the most of this, disabled people should be fully involved in the implementation of the UNCRPD as stated in Article 33. Specifically, the workshop recommended the following steps to ensure access to justice in Sierra Leone:

1. Raise awareness of lawyers and all other professionals to increase access to legal aid for people with disabilities
2. Raise awareness of people working in the justice sector as a whole, and law reform as appropriate, to accommodate the rights of people with disabilities. This comes both with regard to following existing substantive laws, and enacting them where they do not exist
3. Develop and implement comprehensive policies for all people with disabilities, regardless of the cause of the disability
4. Enact legislation on disability issues and rights where it does not exist
5. Ratify the UNCRPD where this has not yet been done
6. Sensitize the whole justice sector from the police to prisons, so that they take people with disabilities into consideration in the application of the procedural law. This recognizes that substantive law (for instance, national legislation) may make provisions for people with disabilities, but that procedural law (for instance, judges’ rulings) might not take these provisions into account. For example, while it may be illegal to discriminate against a blind crime suspect, if police do not supply Braille copies of the person’s statement for signature at the police station, the police could write something that the suspect could not read, and could not be guaranteed was an accurate representation of

“......no person shall be treated in a discriminatory manner by any person acting by virtue of any law or in the performance of the functions of any public authority.” Section 27 (2) of the Constitution of Sierra Leone
his statement. In another example, people who are hearing impaired or deaf might need sound recording systems or sign language interpreters to testify or fully participate in their own court trials.
6. Count me in: pre-conference workshop on data and statistics

...Statistics are essential for sustainable economic, environmental and social development, and public trust in official statistics is anchored in professional independence and impartiality of statisticians, their use of scientific and transparent methods and equal access for all to official statistical information

– Principles Governing International Statistical Activities, United Nations Statistics Division

Research is not the end. The end is a fully inclusive society with no discrimination and people not being excluded from life. Statistics and research are tools. They can be particularly effective used by governments to figure out how to allocate their resources.

– Daniel Mont, Senior Economist, Disability and Development Team, the World Bank

Stand up and be counted: a familiar rallying cry for many social justice movements, not least among those who lobby for full human rights for disabled people. Yet being counted, both physically and metaphorically, is precisely what many people with disabilities have not been able to achieve. Effective disability and development policy relies on accurate statistics about disability prevalence, but there is significant debate about the reliability of almost all the disability statistics from developing countries.

Many pressing questions need answers, and speakers and participants throughout the conference have had to rely on statistics for many of their arguments and to inform their work. At the same time, some very basic questions, such as how many people with disabilities live in developing countries, and how many disabled children in Africa attend school, cannot be easily answered based on existing data.

How to best collect the data that can change this situation was the focus of the pre-conference workshop’s presentations, which covered the issue from a wide range of different viewpoints. Perhaps surprisingly, this statistics workshop was not primarily about numbers, but instead about how definitions of disability influence how it is perceived both by the public and those trying to measure it.

Speaker Daniel Mont, for instance, argued that previous census questions had unwittingly reinforced the medical model of disability, by concentrating on physical conditions rather than on what a person can or cannot do. Jean-Francois Trani echoed this in his contribution on the capability approach to disability measurement, which is based on
a philosophy that considers what an individual can achieve or not achieve within the society around him or her.

The importance of cohesion and comparability arose throughout the presentations. In discussing the World Health Organization’s International Classification of Functioning (ICF), and the work of the UN Washington Group on Statistics, the participants recognized the need for a worldwide set of measures that allow statistics to be understood and believed across cultures. They also pointed out that the ICF and the Convention define disability as a continuum and that, as such, measurements must capture a situation that is in constant flux.

Since not all governments carry out regular national censuses, it was also thought to be vital to develop tools that can be used in many different kinds of sample surveys. These include UNICEF’s Multiple Indicators Cluster Survey (MICS) system, and other surveys specifically on disability or looking at broader demographic and economic issues, defined and conducted by national statistical offices, which can complement other kinds of economic and social research projects.

Questions of methodology are not at all theoretical; they have very real implications for data collection and resulting policies. As Marguerite Schneider showed in her presentation, different kinds of surveys can lead to extremely different counts of people with disabilities. With disability prevalence estimates in one area of South Africa varying from 2% to 12%, the importance of methodology in gathering accurate results becomes paramount.

In summation, Workshop Chair Professor Nora Groce reminded participants that we stand in the middle of an evolving process. One of its goals is to make sure that disability is considered in all spheres of public life. Coming from such a “famished atmosphere,” some stakeholders may feel as if we can only have one disability question in a survey.

“The goal,” Professor Groce reminded everyone, “is not to have one project after another collect fragments of information, but rather to ensure that major population surveys and censuses include disability as a key component in their regular work. When disability-specific data collection efforts are undertaken, it is also vital that there is collaboration and coordination among researchers, organizations and agencies. This would allow us to gather, use and share such information as effectively and efficiently as possible. Unless, and until, we have such data, it will be much harder to engage in meaningful discussion with policy makers in health and development circles, or to plan effective programs or policies for people with disabilities at local or national levels.”

To stress this point to the international disability and development community, and to underline the need for accurate statistics in policy making and service development, the workshop participants came up with a unifying call for action on disability data and resulting development programs.
We call for:

1. Collection of disability statistics using current developments in thinking on disability, measurement and statistics, such as the International Classification of Functioning and the United Nations City Group (Washington Group on Disability Statistics)

2. The collection of more and better statistics for all groups of people with disabilities, particularly focusing on the need for the development of national disability statistics pertinent to children and older people with disabilities

3. Development of national disability statistics pertinent to children with disabilities

4. Medical and therapeutic evaluations following household surveys, to address issues around false positives and false negatives.

6.1 Monitoring child disability via household surveys: the MICS experience

Speaker: Claudia Cappa, Strategic Information Section, Division of Policy and Planning, UNICEF USA

As the world’s main safeguard for children’s rights, UNICEF recognizes that the incidence of child disability is relevant to many areas of its work. These include monitoring the impact of:

1. Improvements in child survival, and the potential that these are accompanied by increases in the prevalence of child disability

2. Childhood exposures to nutritional deficiencies, environmental toxins, infectious diseases (such as malaria, HIV, encephalitis), and trauma

3. Interventions designed to improved child health and development.

In addition, population-based information on the status of children with disabilities is needed to:

1. Identify risk factors, causes and strategies for prevention

2. Facilitate planning of services


To supply the most useful statistics through household surveys, UNICEF uses MICS, or Multiple Indicators Cluster Survey. Its disability module is based on asking parents or caregivers ten questions designed to identify children aged two to nine years old in any cultural and social setting, who have congenital and developmental impairments. The MICS disability module can provide data on the type of impairment (seeing, hearing, language production, etc.) and actual health conditions, such as epilepsy, and activity limitations, such as not walking or playing.

So far, MICS has been used in 53 countries and measured 101 indicators, including nutrition, mortality, child protection, HIV and others. The data can be broken down by background characteristics such as ethnicity, wealth and education and at the sub-national level, and can be used for monitoring progress towards the Millennium
Development Goals and other international commitments.

Like the World Bank’s methods, MICS follows the social model of disability, and looks specifically at activity limitations and participation restrictions within the ICF framework. Data analysis can then assess risk factors, and explore associations between existing impairments and participation in activities such as education, which point toward social barriers to inclusion.

With a reliance on universal human abilities, MICS is cross-culturally comparable. It also relies on caregivers’ ratings of children’s development and behavior, which ensures that answers are relative to their own cultural norms. Analysis has also shown MICS not to be gender biased, making it equally valid for girls and boys.

Under the MICS definition, a child is considered disabled if he or she:

1. Has delay in sitting, standing or walking
2. Has difficulty seeing, either in the daytime or at night
3. Has difficulty hearing
4. Has difficulty in understanding instructions
5. Has difficulty walking or moving arms, or has weakness or stiffness of limbs
6. Has fits, becomes rigid, loses consciousness
7. Does not learn to do things like other children of his/her age
8. Does not speak at all
9. Speaks differently from normal or cannot name at least one object
10. Appears mentally backward, dull or slow.

MICS works through a two-phase design, meaning that if the questions indicate a possible impairment, then this must be verified by a clinical evaluation. This leads to several limitations in MICS, namely that it can be hard to provide a diagnosis in countries where access to health care resources are limited, and that it tends to pick up more severe impairments such as intellectual, motor and seizure disabilities, but can miss milder visual and hearing impairments. Its validity for evaluating autism and attention deficit disorders is also not yet established.

50 For information on the World Bank’s approach, please see the report of the next statistics presentation in this section.
MICS has recently been used by a global study on child disability by UNICEF and the University of Wisconsin in the USA. The results are based on data from 20 of 53 countries participating in MICS3, with 205,674 children screened. Findings show the correlation of disability to a wide range of variables, including gender, nationality, national region and health interventions, such as iodization of salt and supplementation with vitamin A.

Some interesting challenges to prevailing theories have emerged from this data, such as finding no consistent relationship between maternal education/household wealth and screening positive for disability across countries. In addition, salt iodization is not correlated with the percentage of children screening positive, and neither is more violent methods of discipline.

This study has shown other factors related to disability. For instance, children from minority populations within countries often have a higher rate of disability. Children who have never been breastfed have a higher rate of disability in every country, as do children who have never taken vitamin A supplements. In almost every country, the number of children with disabilities who did not attend school outnumbered those who did.

The next steps for data analysis of disability among children in developing countries include recognizing the need for medical follow-up to validate data, and guaranteeing treatment for children at risk. It is also important to keep addressing issues of participation and discrimination, and to create partnerships that can bring about synergies in data collection.

To learn more about MICS and UNICEF’s role in disability data collection, please visit www.childinfo.org.

### 6.2 Measuring disability: from concept to operation

Speaker, Daniel Mont, Senior Economist, Disability and Development Team, the World Bank

Questions of how best to collect data strike at the heart of one of the most potent debates within the disability movement: whether concentrating on measuring and quantifying impairments promotes the medical, rather than the social model of disability. This is the thesis of Daniel Mont, who pointed out that taking a medical model approach when designing surveys and censuses, keeps the focus on individuals themselves rather than how they interact with their environment. This can lead to interventions being done at the personal level, including medical care and individual adaptation, instead of considering the overall physical, cultural, and policy circumstances.
One problem with medical model type data collection is its focus on diagnoses. Since not everyone is aware of or has a diagnosis for impairment, the survey will never capture all the relevant information. Even if a person can accurately report a diagnosis, this does not necessarily provide information on conditions that have a wide variety of effects. Interventions such as rehabilitation, which cannot cure but can improve a person’s physical functioning, and thus impact on his or her social interaction, are also not taken into account. Finally, medical model questions will also miss socioeconomic factors that are either a cause of, or caused by, the impairment.

Even using the word disability can miss people in a census, Dr. Mont argued. For instance, some people may not consider themselves or their family members to be disabled, particularly if the impairment is associated with age, and others might not understand what the word means. People may interpret disability differently to the people who designed the questionnaire, and the word itself can carry a stigma and so be avoided for personal and social reasons.

Partly in response to these issues, the World Health Organization (WHO) developed the International Classification of Functioning (ICF). This system is an attempt to capture the social model of disability, which is based on a person’s ability to function within society rather than a specific impairment, and considers a person’s bodily function and structures, activities and participation. It does not measure disability and is a classification rather than a measurement system, meaning that disability is not considered as separate from the environment.

The three elements of the system are designed to interrelate and be considered simultaneously:

**Body function and structures** consider the physiological and psychological function of body systems. The ICF allows specific recording of detailed functional abilities and impairments that are not linked to a cause. For example, issues of “fluency and rhythm of speech functions” could result from stuttering, stroke, or autism.

**Activities** describe someone’s functioning in his or her environment as a whole person, as opposed to focusing on the function and structure of body parts. The activities considered range from basic (such as walking) to complex (for instance, work and schooling), and cover tasks an individual can do that require multiple body functions.

The **participation** element allows for inclusion of higher order activities that involve integration in the community.

When considering how to put these principles into use, remember that good survey and census questions capture specific concepts in a uniform way, and that the purpose of measurement determines the method. The first question to consider, therefore, is why do you want to identify disabled people? From this flows the issue of whether it is disability or functioning that is most important in each particular research initiative.
Researchers can then decide which section of the ICF model is most pertinent – body function, activity, or participation. Does the survey want to consider health conditions and their causes? What attention is to be paid to the environment, both general and personal (for instance, are assistive devices available)? What is a feasible survey length and sample size, and what is to be measured compared to what will be identified through analysis?

In practice, a census may not allow much space for questions on health and disability. The option to compare results across countries, across demographic groups and across time then becomes highly desirable, so questions should be chosen carefully.

The UN Washington Group on Statistics (a temporary organization set up by the UN in 2001, through which representatives from national statistical agencies come together to address issues around disability and statistics) decided that measurement within a census should determine “Equalization of Opportunities.” This approach leads to basic activity questions, because relatively few questions can yield some important information and opportunities for cross-referencing. Examples of these include:

**Core questions:**
- Do you have difficulty seeing, even if wearing glasses?
- Do you have difficulty hearing, even if using a hearing aid?
- Do you have difficulty walking or climbing steps?
- Do you have difficulty remembering or concentrating?

**Additional questions:**
- Do you have difficulty (with self-care, such as) washing all over or dressing?
- Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

**Response categories:**
- No – no difficulty
- Yes – some difficulty
- Yes – a lot of difficulty
- Cannot do at all.
Analysis can then make links that show, for example, that if people with activity limitations (such as difficulty walking) have lower employment, education and income, then there are barriers that lead to unequal opportunities. That is, disability. The prevalence rate generated must be understood in those terms, and this combination of measurement and analysis is consistent with the social model of disability.

The World Bank has chosen to follow this approach, and to support others to do so as well. Their first initiative in this area is to support the work of the UN Washington Group on Disability Measurement, both with census questions and other more specialized measures. They are also developing indicators for evaluating the impact of development activities on people with disabilities, and collecting primary data for use in planning, monitoring and evaluation.

Recently they have used these techniques in evaluating a microfinance program for disabled people in Andhra Pradesh, India, and in doing needs assessment for an earthquake relief project in Bangladesh. They are also experimenting with using a “Ten Question Screening Instrument” (TQSI) in collaboration with the OECD in Bangladesh, Ethiopia, Cambodia and other countries.

To support governments in collecting disability data, the World Bank has started an online training course[^51] and video for Latin America, and held regional training sessions in South and Central Asia. Disability surveys are another focus, and they have helped with projects in Bangladesh, India, Vietnam, Uzbekistan, Indonesia, Bosnia, Ecuador, Bolivia and Yemen, as well as collecting data for educational management information systems in Cambodia, Vietnam, Indonesia and Mongolia.

### 6.3 Review of surveys in Africa that capture disability

**Speaker:** Oumar Sarr, Social Statistics Expert, African Centre for Statistics, UNECA

Every African country, like all countries, has a national statistics office (NSO) to collect and analyze social and economic data, following internationally accepted methods and standards. Much effort has gone into empowering African NSOs and making them autonomous agencies, with more power to coordinate their national statistical system regardless of national political climates. African NSOs, however, may still lack some of the resources, staff and knowledge of methodology they need to obtain and disseminate the most accurate information.

Many NSOs make economic statistics a priority and just measure some common social indicators, including those on education, health, poverty and living conditions, as these

are often used to support poverty reduction strategies. Gender, environment and good governance are new areas for African NSOs and they need support to strengthen their data collection practice in these subjects.

Disability information would be commonly collected along with other social data during population and housing censuses, which are the primary source of information about the number and characteristics of a given group of people. They are carried out every ten years and are often the only statistical operation that covers 100% of a country’s population. Such censuses remain the sole source of socioeconomic characteristics in many African countries, and also provide a sampling frame for other statistical surveys.

The UN principles and recommendations for population and housing censuses stressed that social issues be included in the 2010 round of censuses. However, NSOs must check the sensitivity and appropriateness of the survey framework, and determine whether specific questions are applicable for the census. Because of stigma within societies and cultures, whole sets of questions could be jeopardized. As other speakers also noted, there may not necessarily be a common conceptual framework for data or for definitions of disability, and countries use different approaches to capture disability information.

In common with the previous speakers, Mr. Sarr also recommends that censuses use the “difficulty” rather than “disability” approach. Questions can measure limitations in basic activity functioning, and then be cross-referenced with questions on performance of, or participation in, organized activities such as education or work. Persons who are at greater risk than the general population for experiencing restrictions in performing specific tasks, or participating in important activities, can then be identified, and a larger picture of the impact of impairments and social barriers can be formed.

For international comparison, it is considered appropriate to have questions on four different domains:
1. Walking
2. Seeing
3. Hearing

Additional domains to be considered include:
1. Upper body functioning of the arms, hands and fingers
2. Mental/psychological functioning, trauma.

Mr. Sarr then discussed the many different kinds of surveys currently being used in Africa, and the kind of information on disability that they yield. Disability information from other surveys typically covers individuals and households and collects data by disability type, cause and severity. The typical response rate is 70–100%, but it is worth noting that most socioeconomic surveys other than full censuses do not include questions on disability. Survey types include:
1. **A Demographic and Health Survey** (DHS) will consider common health indicators and usually sample 3,000 to 5,000 households. The cost of such surveys is often high. National governments and partners such as USAID usually sponsor the survey, with a periodicity of four to five years. It does not always include disability questions.

2. **A Multiple Indicator Cluster Survey** (MICS) (Please see the above report of Claudia Cappa’s talk on this subject) focuses on women and children’s health. Samples range from 3,000 to 5,000 households and sometimes include questions on disability. The cost of a MICS survey is high, so they are usually sponsored by countries, and the main partner is UNICEF.

3. **Household Living Conditions Surveys** (HLCS) examine poverty and living conditions, with samples varying from 1,600 to 8,000 households. It is an expensive survey because of the length of data collection (almost 12 months), and is sponsored by multilateral and bilateral organizations such as the World Bank, European Union and DFID. Such surveys are typically done every four to five years and sometimes include disability as an issue.

4. **Core Welfare Indicator Questionnaires** (CWIQ) also focus on poverty and living conditions, with samples varying from 3,000 to 15,000 households. It is a light version of HLCS and the data collection duration varies between two and four months. This kind of questionnaire is cheaper to implement, but also attracts sponsorship from organizations similar to those that sponsor the HLCS. These surveys usually yield some data on disability, but it is not disaggregated by type of impairment.

5. **An employment survey** considers employment indicators only, and usually samples approximately 3,000 households. It can be expensive and is often sponsored by governments and the International Labour Organization. Such surveys are not common in Africa, but do sometimes include data about disability.

6. **Agricultural surveys** are more common, and focus only on agriculture, with a sample of approximately 2,000 to 5,000 households, giving a picture of a large part of the active population (more than 80% of the active population in the region work in the agricultural sector). The cost of agricultural surveys is high and the Food and Agriculture Organization often sponsors them every three to four years. Disability questions are rarely covered in this kind of survey.

Given the wide range of types of surveys done in Africa, and the relative lack of funds available for them, including for the recommended population and housing censuses, Mr. Sarr concluded that disability stakeholders must advocate for the collection of data on disability in as many surveys as possible. He also argued for harmonization of definitions and methodology so that data can be compared across subject areas and across countries.
6.4 Capability and disability: an approach for a better understanding of disability issues
Jean-Francois Trani, Researcher, Leonard Cheshire Disability and Inclusive Development Centre, University College London

Previous speakers at this workshop discussed the medical and social models of disability, and the challenges that both of these present to accurate collection of data on disability. The speaker in this presentation, Jean-Francois Trani, introduced another perspective – moving from the social model to the capability approach.

Data collection in developing countries presents many challenges, Dr. Trani commented, not least of which is choosing the right measurement tools. Another complication is how best to measure not just disability prevalence, but also living conditions. The capability approach framework can help with this, by defining disability and impairment and also clarifying the best methods of assessment in a given situation. This compares favorably with other approaches, which all have both strengths and limitations.

The medical model (or the individual model) compares impairment to a physical norm, and the danger is that tools can end up measuring only a few categories of impairment, leading to a low prevalence rate. Stigma can also lead to underreporting and underestimates of disability prevalence.

The social model has helped achieve great progress within the disability movement in terms of advocacy, but also presents certain limitations for measurement. First, looking at levels of functioning in a given context can imply that society needs to be redesigned, rather than considering the implications of a specific impairment. In some cases, such as in Australia and the UK, society has already been somewhat redesigned, and there are disability prevalence rates of up to 20%. Some people in these societies are considered to have a disability in order to benefit from certain policies, yet from the point of view of the social model they are not actually disabled, because they are largely integrated into society.

The social model also does not consider a disabled person’s functioning in his or her environment. This is why Dr. Trani suggests moving towards the ICF model, which looks not only at impairment, but also at personal factors and the environment, thus taking interaction with society into account. Yet a survey that uses the ICF must ask many questions, and right now there is no single data collection tool that includes all its aspects. Some researchers also feel that the ICF needs to be adapted according to the cultural context in which it is used.

The capability approach, as developed by the economist Amartya Sen, gives a wider view – it considers not only disability issues, but also the needs of people with disabilities. Constraints, choices and values, as well as functioning, are all part of its analysis, and it moves from considering what a person can do physically to looking at the range of
possibilities open to someone in a given context. It then progresses to exploring the potentialities of how an individual develops his or her place in society.

The philosopher Martha Nussbaum takes the system further, by proposing a list of ten central capabilities, including life preservation, good health and body integrity. This takes physical limitations into account, and also explores the ways in which societies can compensate or allow people with disabilities to benefit from central capabilities. In this way, she can address situations such as severe mental health problems and intellectual disabilities.

There are limitations to the capability approach, however. First, it needs to look at an individual’s potential, so in terms of measurement it leads to questions on both activities, and on the person’s perception of opportunities or limitations within society. It must also look at vulnerability, which may be defined as a risk of falling into a lower level of wellbeing, and this too necessitates further questions. Finally, studies using this approach should also consider the opportunities and constraints offered by a given environment. All of this leads to a complex and long measurement instrument, which raises concerns about how it can be practically applied.

A further complication is that the capability approach concentrates very much on individuals, both disabled and non-disabled, but does not include the possibility of collective action. Nor does it examine how people can connect with society and what responsibilities society has towards its citizens. Dr. Trani and the co-author of his paper on this subject, Professor Jean-Luc Dubois, suggest complementing the capability approach with a phenomenology approach.52

This would allow for a systematic view and includes all behaviors and interactions inside a given cultural context. It also permits analysts to look at rights and obligations, the intentions behind actions and the full range of emotions and beliefs that constitute the reality of human life. In this context, the freedom exercised by the person with disabilities becomes a specific phenomenon to be observed and analyzed. The negative implication of combining these two approaches is that it would make measurement even more complex.

The first issue to consider within this new framework is how social and political collective capabilities could emerge from the consideration of several different individual capabilities. For the statistician and social scientist, this creates a problem of aggregation. How do you go from considering attributes of an individual that you can measure with an instrument, to understanding collective capabilities such as how people interact? The next task is to measure whether such interaction increases or decreases each person’s capabilities. A study done by P.B. Anand in India in 2007, started to tackle these issues by

52 Phenomenology is a movement in philosophy that has been adapted by certain sociologists, to promote an understanding of the relationship between states of individual consciousness and social life. As an approach within sociology, phenomenology seeks to reveal how human awareness is implicated in the production of social action, social situations and social worlds (Natanson 1970), http://hss.fullerton.edu/sociology/orleans/phenomenology.htm, California State University, Fullerton.
looking at capabilities for using metered water collectively, and considering the model of social relations in terms of public health and development.\textsuperscript{53}

The second issue is to look at responsibility. Two types of responsibility have been identified: that of an individual after an event happens (retroactive) and a prospective dimension – the feeling of each person in a group or society of being responsible for the wellbeing of everyone else. Will individuals limit their own wellbeing to improve the wellbeing of society? This issue has been well explored by the philosopher Emmanuel Lévinas, who considers wellbeing as being each person’s individual responsibility in society.\textsuperscript{54}

Dr. Trani tried to carry out an exercise of this kind in Afghanistan, and can offer a few examples of how to integrate this kind of approach. For example, they asked questions on whether people found education useful, which can uncover if people value education. To examine opportunities, they asked what people believed their situation would be like in five years. If it will be better, then what new opportunities will people have? If it will be worse, then what are society’s restrictions? If people with disabilities have been mistreated, then what are the motivations of the people who mistreated them?

Defining an instrument for data collection in this context is extremely complex. More variables are needed and the volume of information collected is much higher than in other kinds of surveys. This has consequences for both measurement and analysis, and researchers must consider issues such as choice, agency, capability and behavior and the local context.

To analyze the data collected, you could use micromodeling, predictive modeling and other techniques, to estimate people’s potential capabilities. Extrapolating from all potential capabilities that exist allows the creation of a typology of possibilities. Overall recommendations from such a study would look at ways to increase every person’s capabilities, particularly those of people with disabilities.

Time is another variable to be considered. To analyze it, researchers must look at how people’s situations improve or deteriorate through time in terms of achievements, potentialities and restrictions. One way to do this is through national surveys over a period of time, such as repeating the 2005 Afghanistan survey in 2008. This can be expensive, and dangerous in some circumstances (including Afghanistan), and so following a control group of people with disabilities through smaller surveys over a certain period can be easier. Both of these kinds of tools exist, and have been set up in several countries to tackle different issues. More research is needed to apply these methodologies to the case of disability, though, and to develop the most efficient tools for this kind of data collection.


6.5 Disability measurement and statistics — the state of the notion

Speaker: Marguerite Schneider, Research Manager, Human Sciences Research Council of South Africa

A. The issues to consider

There is growing interest and an increase in research into disability statistics, contends Marguerite Schneider, but progress in this area must accelerate even further if the comparability of statistics at regional and global level, required by the UNCRPD, is to be reached. Agreeing with the other speakers on this point, Ms. Schneider commented that we are now not sure if we are measuring the same thing, and cannot readily compare statistics across countries.

Generally, there are three levels of factors affecting disability statistics:

1. Population – well understood
2. Individual – not well understood
3. Methodology – reasonably well understood.

From the population point of view, the world’s current aging population means that the prevalence of disability is rising. The level of development of health care services in a country has a direct influence on this trend, because of the varied capabilities in managing injuries and illnesses. Curable health conditions can also sometimes lead to disability if not treated, for instance, untreated middle ear infections can result in permanent hearing loss. In more developed countries, higher levels of industrialization and car use have led to higher rates of accidents and injuries.

At the individual level, a person’s overall sense of independence and identity, social inclusion or exclusion and overall disadvantage experienced (for instance, limited access to education and employment), all contribute to disability and need to be recognized and measured. Pertinent issues include:

1. Poverty resulting from the impairment
2. Access to health care services and having a diagnosis to report
3. Age
4. Cultural beliefs and notions of health and functioning
5. Racial, ethnic and gender identities
6. Level of education
7. Socioeconomic status
8. Access to knowledge and resources.

Methodology becomes particularly important when considering the wording of questions — for instance using the terms “have” versus “suffered” and “disabled/disability” versus “difficulty.” The response option is also crucial for getting the best data, for instance, only offering the option of a yes or no response does not include enough
opportunity for giving details of partial impairments, and results in fewer people reporting disabilities.

Increased and graded response options, from “no difficulty” to “extreme difficulty/unable to do” make people with mild difficulties more comfortable saying yes to a question. On the other hand, using the word serious within a question can create problems, as people have very different ideas of what levels of difficulty may be interpreted as serious.

As always, the social stigma of disability can influence answers. One survey question was worded, “God forbid someone has a disability, but if they do are they...?” Answers to such a question can hardly be expected to reflect true prevalence rates. Other questions that label people as deaf, blind, crippled or mentally retarded may also lead to a lower response rate about impairments.

It is better to consider difficulty as a complex, multidimensional phenomenon covered by a range of different questions as is done in the World Health Organization’s International Classification of Functioning. Since there is no single definition of disability, there can be no single measurement or statistic – we need to understand what we are measuring to understand the data.

B. The impact of different methodologies in South Africa

In South Africa, several studies have looked at qualitative and quantitative information on how people understand and view the notion of disability, and how this affects their answers to different questions on the subject. It also considered what frame of reference people use in answering questions on disability. The research examined three different sets of questions on how people rate their own situation, which were:

1. “Are you disabled?” (Yes/no/sometimes)
2. South African Census 2001: “Do you have any serious disability that prevents your full participation in life activities (such as education, work, social life)? MARK ANY THAT APPLY – None, Sight, Hearing, Communication, Physical, Intellectual, Emotional” (with yes/no response options)
3. Washington Group (WG) Short Set, which asks about “difficulties” in doing a range of activities, including:
   a. Do you (or does the person) have difficulty in doing any of the following (because of a health condition)?
      1 = No difficulty 4 = Unable to do
      2 = Some difficulty 5 = Don’t know
      3 = A lot of difficulty
   b. Seeing (with glasses if he/she wear(s) them)?
   c. Hearing (with a hearing aid if he/she wears one)?
   d. Walking a kilometer or climbing a flight of steps?
   e. Remembering?
   f. Concentrating?
g. With self-care, such as washing all over or dressing?

h. In communicating in his/her usual language, including sign language (i.e. understanding others or being understood by others)?

i. Joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?

In assessing the results, the study considered how easy it was to answer questions about difficulty and differences between responses for the three question sets. Specific issues included determining what sectors of the population are counted in or out for each of the three question sets, and the effects of having different response options – for example binary versus four response options.

One of the studies involved six focus groups across urban and rural areas and among different language groups. Twenty-one included adults answering questions about themselves, with nine groups calling themselves disabled, six groups unsure and six groups, non-disabled. Five groups were made of parents, with three groups having disabled children and two groups having non-disabled children.

Each participant completed a standard questionnaire before the group met, and then the group discussed the definition of disability and difficulty and reactions to questions. Sessions were recorded and analyzed thematically using Atlas-ti, a qualitative data analysis tool.

The national survey covered 1,508 Enumeration Areas (EA), with four households in each EA, and was a population-based survey of 6,032 households, of which 4,705 yielded useable data. Over 11,000 individuals aged 15 and older answered three questionnaires:

1. a household questionnaire: head or most knowledgeable member of the household
2. an adult questionnaire: all household members 15 years and older who could respond for themselves
3. a Living Standards Measure (LSM) questionnaire: respondent on the household questionnaire.

Interesting differences in the way respondents viewed difficulty and disability became clear from the responses to this survey. Participants concluded that disability is:

1. Permanent
2. Visible and physical
3. Not “curable” or “solvable”
4. “Cannot do anything by themselves” versus “can’t do” only in impaired domain of functioning
5. “Them” and “us” across all groups
6. Not a positive connotation.
Responses to the idea of difficulty were very different, however:

1. Difficulty is less severe than disability and can be solved
2. Disability includes difficulty, but difficulty does not include disability.

In general, people thought that the questions were not too long, easy to answer and reflected their own lives. They also liked using terms such as “usually” or “normally” when talking about functioning with and without assistive devices.

As is shown in the chart below, responses to disability questions using the three different sets of methodologies, led to very different measures of disability within the community. For instance, out of all the people who said that they were unable to do one or more of the activities mentioned in the Washington Group survey, only 61% had defined themselves as disabled in the national census, meaning that the census had potentially counted 39% of disabled people as non-disabled. Among the people who reported that they had a lot of difficulty with certain tasks in the Washington Group survey, only 47% had defined themselves as disabled in the national census, potentially leaving 53% of disabled people out of official statistics of disability.

Such differences have a huge impact on official figures and the policies that are based on them. In the Washington Group survey, the response on one or more activities out of seven activities was:

1. 67.7% of adults = no difficulty
2. 19.9% of adults = some difficulty
3. 9.9% of adults = a lot of difficulty
4. 2.5% of adults = unable to do.

Using these measures, 32.3% of the population over 15 years old has some sort of disability. When the stricter definition of the disabled population is used (a lot of difficulty or unable to do) then 12.4% may be considered disabled. Even this figure is much higher than official estimates in South Africa.

Based on these findings, the questions for the national census in 2011 are being redesigned to use the difficulty model. The aim is for this census to use much clearer measures based on a better understanding of what we are measuring. They will also be inclusive measures that are more mainstreamed across social groups, and allow extensive analysis that leads to more effective disability policy and inclusion.

6.6 Data collection, gaps and issues: statistics relating to poverty and disability
Speaker: Imran Nazir Rana, National Coordinator, Leonard Cheshire Disability and Development Programme, Pakistan

Considering the situation for disability statistics in Pakistan, Imran Nazir Rana believes that there is a lack of reliable data. The most recent census in Pakistan was in 1998, which
reported a disability prevalence rate of 2.49%, a figure thought by most people working in the disability field to be far too low.

The census included only one question on disability, which was phrased, “do you have a disability?” As other speakers have noted, this kind of wording commonly leads to underreporting, since people consider “disability” to be very serious and may not report less severe impairments. Disability may also be shameful in certain societies and so people may choose not to describe themselves in this way. This wording can also lead to undercounting of older people who have difficulties carrying out some tasks, since these problems may be seen as a normal part of the aging process.

National policies and programs have been designed based on these possibly inaccurate statistics, leading to insufficient resources being available for people with disabilities. For example, there is a 2% quota for employing people with disabilities in government departments, and funds allocated for rehabilitation programs also work on a basis of providing service to 2% of the population. The national budget for education for children with disabilities is now actually falling, because of overall cuts in government spending, but may have been insufficient to cover the true numbers of disabled children even before the budget cuts.

If we accept the contention that poverty is both a cause of and caused by disability, there is a growing need to conduct a systematic and scientific survey to uncover accurate data on disability prevalence in Pakistan. This could take the form of a single, reliable tool or method for data collection that could be used by all stakeholders.

The problems in both counting and providing services for disabled people in Pakistan was further complicated by the devastating earthquake that hit the North West Frontier Province in October 2005. Among the earthquake’s survivors, 4.35% of men and 4.28% of females became disabled, but none would have been covered by the 1998 census. These statistics are also not completely reliable, because different agencies used different measures to count the number of people affected.

There may be much to learn from the measurement process at grassroots level, where a number of local, national and international agencies in the earthquake-affected areas are trying to identify and count people with disabilities. Some of the common methods used to collect the data related to disability are:

1. Working with community members on information gathering and reporting
2. Collecting and analyzing registration forms used by organizations to register people with disabilities
3. Checking referrals of people with disabilities from other organizations and individuals for help and services
4. Female health workers/visitors reporting disability after household visits
5. Persons with disabilities who directly reach out to the organization’s office for assistance
6. Field workers working for organizations at grassroots level to collect the data and information about the PWDs in working areas
7. Survey method, using questionnaires; however, the validity and reliability of the identification tools is under consideration.

Using these approaches in addition to other improvements in census taking and surveys, discussed by other speakers in the workshop, a single, reliable measurement program could be devised. Policy makers and other disability stakeholders could then use one single method for collecting data in all parts of the country, leading to poverty reduction and disability programs that are uniform from region to region and reach all Pakistani citizens equally.

Some workshop participants wondered whether waiting for accurate statistics to be gathered might hinder the development of effective disability and development programs in the short or medium term. Others even questioned whether a more accurate knowledge of disability prevalence has actually had a positive impact on practice or service delivery. The response to this came from participants from Brazil, whose experience is that better statistics have led to more inclusive policy.

There was also discussion as to whether it is better to measure disability in national surveys, such as the census, or if disability specific surveys are more effective. Participants again referred to the Washington Group recommendations, and suggested that census takers and other researchers develop longer versions of their questions. The information gained, they believe, will lead to inclusive measures.

How much does a particular impairment interfere with participation in the community? How many disabled children attend school in sub-Saharan Africa? Does the association between poverty and disability vary by country or region in Asia?

Unfortunately, nobody knows. And without answers to these and other questions like them, implementing effective disability and development programs and policies remains a challenge. Since understanding a situation is a prerequisite to changing it, addressing the worldwide lack of clear data about the prevalence and consequences of disability must become a priority.

6.7 Survey research in Afghanistan and Cambodia on youths with disabilities

Speaker: Jean-Francois Trani, Researcher, Leonard Cheshire Disability and Inclusive Development Centre, University College London

In countries as far apart in geography, history and culture as Afghanistan and Cambodia, participatory research in which people with disabilities studied the needs of other disabled people, has yielded similar valuable results, asserted Jean-Francois Trani.
Several things made the design and implementation of these studies similar to each other, and also unusual among disability research projects. Both were informed by the ICF and looked at a range of environmental factors. Both also used the capability framework inspired by Amartya Sen to consider disability within the wider spectrum of human development and the wider participation of people with disabilities in society.

Each study had a different purpose: in Cambodia, Handicap International (HI), which was providing physiotherapy services to children, wanted a better understanding of children with disabilities’ rehabilitation and other needs. The country had faced a long conflict that destroyed its infrastructure, which is now being rebuilt, and a socioeconomic survey had established a disability prevalence of 4.7%. The survey was thus designed to explore how HI should develop their programs to best meet disabled people’s needs. In Afghanistan, a range of stakeholders needed information to tackle the needs of people with disabilities as they themselves expressed them.

The studies began by organizing those involved into qualitative and quantitative study groups, to come up with objectives to assess: prevalence, livelihoods, education, service access, income, self perception, and social participation.

For both teams, the idea was to expand choices of people with disabilities in their cultural, economic and social environments. Questions in the surveys considered impairment, activities, participation, and, in Afghanistan, a control group of non-disabled people were included.

The survey teams had similar training, which was one month long and based on the inclusion of people with disabilities in the research teams, and sensitizing interviewers to disability issues. Differences included the fact that the survey in Afghanistan was a national exercise, so researchers went all over the country and interviews could range in length from 30 minutes to two hours. The Cambodian survey just targeted children, was held in only a few provinces and used shorter interviews.

The studies uncovered some striking similarities and some striking differences between the two countries. For instance, exclusion of children with disabilities from school in Cambodia is 45%, while it is 64% in Afghanistan. In both countries, however, more girls than boys are excluded. Again in both countries, when girls do go to school, they progress further in the education system. To a certain extent, if by comparing contexts in which surveys reveal similarities, you can define recommendations for policy makers that could be very similar across continents.

For instance, certain activity limitations are associated with higher levels of school exclusion in both countries. In Cambodia, children who have difficulties remembering things are most excluded from school, and children with trouble concentrating are most included. Sensory limitations and mental difficulties are also associated with a higher level of inclusion in both countries.
Access to health services in both countries is limited by a lack of equipment, inadequate staff training in disability issues, high costs to service users and the remote locations of health centers. All of these findings can help disabled people’s organizations lobby their governments to address these issues, and also inform direct recommendations to policy makers.

The participation of people with disabilities in the whole research process was key to the success of both of these studies. Both used the ICF, and so measured the same typology between difficulties, impairments and health conditions. As stated in Dr. Trani’s other presentation, this approach helps to identify or screen difficulties, but doesn’t help to look at policy issues, unmet needs, aspirations, values, capabilities and increasing freedom of choice among people with disabilities. To take this forward most effectively, people with disabilities will need to participate in the research analysis, and the promotion of its findings within governments and civil society.

6.8 Effect of the SAFOD living conditions surveys on disabled people’s lives.
Speaker: Alexander Phiri, Director General, SAFOD

“Are you not embarrassed?” This is how Alex Phiri, Director General of SAFOD, the Southern Africa Federation of the Disabled, and speaking from the floor of the conference room, began his workshop presentation. “Can you answer me, are you not embarrassed that I’m not up there and I had to come down?”

Mr. Phiri was talking about the fact that the podium at the UNECA Conference Centre in Addis Ababa, where the other speakers were sitting, was not wheelchair accessible. This is not the case for the toilets, which are. “I think that this meeting, or rather our engagement here, will not be complete if we do not send a message to the UN,” he continued, “that it is not only toilets that should be made accessible for disabled people, but it’s all features in a building.”

These comments served as a good introduction to Mr. Phiri’s talk about how human rights for people with disabilities are advanced by SAFOD’s research program. SAFOD coordinates disability organizations in ten Southern African countries: Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe.

Human rights promotion is a core area of their work, which is the reason why Mr. Phiri feels so strongly about pointing out issues such as the inaccessible podium. SAFOD also has programs in:

1. Raising awareness about disabled people’s living conditions
2. Poverty alleviation
3. Building capacity of disabled people’s organizations
Most recently, SAFOD has embarked on a major research program that includes building partnerships with researchers.

The philosophy and founding principle of SAFOD is that disabled people must be at the forefront of their own development, including research. This is critical, Mr. Phiri believes, because when people represent themselves, such as demanding the improvement of this building, they raise awareness of disability issues more effectively than others who speak on their behalf. This leads directly to becoming part of governments, at which point mainstreaming begins to be understood and implemented. This, he thinks, is also a goal of the UNCRPD.

SAFOD chooses not to define disability. People who have a disability, Mr. Phiri contends, do not have a problem with it and do not need to spend their time defining it. “It is only those who are afraid of becoming disabled who want to define what it is and how you can measure it against other people,” he added.

Instead, SAFOD has run a series of representative studies on living conditions among people with disabilities, which are the result of international cooperation between SAFOD and the Norwegian Federation of Organizations of Disabled People. The Norwegian partner has mobilized money from the Norwegian government and encouraged researchers to work with them. This collaboration is noteworthy, because disabled people have the money and power to engage or disengage the researchers, something unusual even in other research on disability.

The studies collect and analyze data for the specific purpose of improving the circumstances of people with disabilities, primarily using it with governments and planners to influence their policy and practice. Without such findings, Mr. Phiri believes, DPOs can go on advocating and advocating without achieving their desired results. “At the end of this meeting,” he proposed, “we can do some quick research. Look behind the podium and see how many people here are not able to go on it. Then present this to the UN.”

SAFOD studies have so far been sponsored in Zimbabwe, Namibia, Zambia, Malawi, Mozambique, Lesotho and Swaziland, with the ongoing support of the Norwegian government. In each country, the studies give an overview and comparison of the situation for people with disabilities and non-disabled people. Personally, Mr. Phiri does not believe that people with disabilities have activity limitations, and so the studies have not been framed in this way.

Rather, he contends, activity limitation is about those who create an environment that limits disabled people. “So far,” Mr. Phiri continued, “the other presenters have not talked about what limits the disabled person – such as not being able to reach the podium. This is not my problem, it is the problem of the people who designed the building with limited thinking.” Following this orientation, the studies looked at specific questions relating to
the day-to-day lives of people with disabilities. For instance, why do fewer children with disabilities than non-disabled children attend school?

Equality is a hallmark of the SAFOD research—people with disabilities participate equally as researchers, managers and subjects of the research. There may be a question of user control here, contends Mr. Phiri, who believes that people with disabilities are not truly helped by being used only as subjects for other people’s research. For this reason, he congratulated the previous speaker, Jean-Francois Trani, for also using people with disabilities as researchers.

The impact of the research program on SAFOD itself has been noticeable. First, it has given them and their partner organizations valuable experience that will empower them to conduct further research. The long-term engagement of researchers has also helped raise awareness of how other researchers can work in partnership with disabled people. SAFOD conducted training courses to promote a basic understanding of research methodology and application, so that their DPO partners begin to understand what research is about and how to apply it in various situations. The disabled researchers also earned money through their activities, which helped them economically. “A lot of capacity has been built through this process,” believes Mr. Phiri.

Practical examples of how the research results have been used include the case of Namibia, in which the government’s planning commission has asked people with disabilities to help translate the research results for the planning process. In doing this, people with disabilities are being included in planning the country’s development. In Malawi, the research has helped the government come up with inclusive policies in many areas. One negative side to the research has been raised expectation among people with disabilities that have not yet been met.

These developments, and the research results themselves, have also attracted media coverage of disability issues. Previously, newspaper stories about disability were often tucked away near the sports column, but now they are coming closer to the front pages. In Malawi, SAFOD and its partners met with the media and were asked all sorts of questions about disability, showing the journalists’ lack of understanding. One reporter, for example, asked if it is true that disabled people are short tempered. SAFOD has seen this kind of ignorance change slowly, however, and can credit the research projects and their implications for it.

The research program has also helped SAFOD and its partners inform their positions on a number of issues. Moving from research to practical issues adds credibility, Mr. Phiri feels, because they can argue on the basis of something that has been found to be true. For instance, they have used study results to raise awareness among teachers and in rural areas, head teachers have come to understand why schools do not enroll disabled children, and that children with disabilities deserve an equal education. Anyone interested in the specific results of the SAFOD studies can get figures from study reports for each country from the SAFOD website, www.SAFOD.org.
7. Not just the voice, but the heart and soul of the conference

The Young Voices Project

“The Convention is the step towards changing attitude and perception, which is the main objective of the Young Voices Project, and ensuring that societies recognize that all people must have equal opportunities to reach full potential, instead of considering persons with disabilities as objects of charity and pity. Most importantly, the United Nations 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 freedom by all persons with disabilities, and to promote respect for our inherent dignity.”

– Daintowon Pay-bayee, Young Voices participant from Liberia

During the conference’s speeches and workshops, between sessions and behind the scenes, 18 young people with disabilities aged 16–25, from 18 different countries, were exploring their rights and learning how most effectively to tell their own stories. They were part of Leonard Cheshire Disability’s Young Voices program, which supports young disabled people to form groups in their own countries, to campaign for the ratification and implementation of the UNCRPD and advocate for disability rights.

Their presence set this conference apart from the usual international meeting. Many had never traveled abroad before and some had never left their home province. Suddenly, they were given the freedom of the UNECA conference center and professional training in video making by two award-winning journalists and filmmakers, Sorious Samura and Ron McCullagh. Their task was to practice using their cameras by interviewing conference delegates and each other, and recording video diaries. Ultimately, their goal was then to go home and make videos about the campaigning work of their Young Voices groups.

The Young Voices participants also gave presentations in some workshops and participated in others. Some surprised other delegates with their passion and eloquence, and their personal stories added a dimension that academic or political papers alone could not cover.

Their ultimate message was that they are the future. Everything being talked about at the conference is about them and people like them, who will carry its goals a long distance in both space and time. By electing a representative, Ephraim Segone of South Africa, as a keynote closing speaker, they also demonstrated that among their number are
the future leaders of the disability movement, civil society and government. The real sense of confidence they gained by realizing that they could achieve and be listened to and that their opinions counted, will be invaluable for future campaigning work.

Specifically, the training they received in a special two-day workshop before the conference, helped the Young Voices participants to understand the UNCRPD, what it means to them and the reality of the ratification and implementation processes in their countries. Further, they learned how to translate their life experiences into advocacy messages and distil their needs and demands into palatable, bite-sized chunks for use in film, newsletters, lobbying and campaigns. Each participant received one-to-one teaching and advice, to help him or her understand the technical, informational and artistic sides of filmmaking.

This will contribute to the dynamic next phase of the Young Voices project, in which their films are being professionally edited and put on the Internet. A total of 26 three-minute films will be produced during the year, with each Young Voices group contributing at least one, and they can be viewed on www.LCDisability.org/youngvoices and on YouTube at www.YouTube.com/youngvoiceslcd. Using a video diary style, the films will include personal stories, commentary and input from other group members, as well as footage of Young Voices group meetings, debating and activities.

Their media and communications training will also help the Young Voices representatives reinforce their existing campaigning activities and initiate new, in their home countries. For instance, in Sudan and Sierra Leone, Young Voices groups have used radio to raise awareness of disability issues among the general public, and to call for changes to the law and to issues over access, education and health care. In Sierra Leone, the Young Voices group has also composed a song advocating disability rights, which is included in the Young Voices website and has been played over Sierra Leonean radio. During the conference, the Young Voices participants from Southern Africa covered conference events in two newsletters that they wrote and produced for delegates. Young Voices participants also contributed an article about their experiences to Disability Studies Quarterly, a journal available on www.dsq-sds.org.
8. Supporting inclusion ratification and disability mainstreaming toolkits, handbooks and guides

What practical steps can I take to mainstream disability in my work, community or country? What have other organizations already done? Has it been successful? How much did it cost and was it worth the money? Where can I get background material to develop my own ratification and mainstreaming strategies?

These are just a few of the questions that anyone working for the ratification and implementation of the UNCRPD might ask. Just before the conference closed, speakers in seven workshops explained how to use ratification and mainstreaming toolkits that have been developed by a wide range of organizations for a wide range of users.

Here, we offer information on how to get copies of these toolkits to use in your own programs. By sharing work that has already been done, we hope to support the work of all organizations joining the international efforts to bring the UNCRPD to life.

8.1 Workshop 1 – DPI ratification and implementation toolkits

Disabled Peoples’ International (DPI) is a worldwide network of disabled people’s organizations with national assemblies in 135 countries, and regional development offices in Europe, Asia-Pacific, Africa, Latin America and North America-Caribbean. DPI has produced two toolkits to use with the UNCRPD, one for ratification and one for implementation. You can access both from the main DPI website, www.dpi.org, and each also has its own web address:

Implementation toolkit: www.icrpd.net/implementation/en/index.htm

DPI’s world headquarters are in Canada and if you do not have access to the Internet, their contact details are:
8.2 Workshop 2 – European Disability Mainstreaming Toolkit (EDAMAT)

EDAMAT (European Disability Action for Mainstreaming Assessment Tool) was developed over a two-year period in six European countries – Greece, Malta, Ireland, Portugal, Spain and the UK – with the support of the European Commission and national groups of disability stakeholders. Its aim is to assess and promote the effective mainstreaming of disability in general policies, laws and programs. EDAMAT emphasizes how to implement the concept of mainstreaming and ensure that the result has a positive impact on the lives of people with disabilities.

EDAMAT is available in five different languages: English, Spanish, Portuguese, Maltese and Greek (text-only). Each language version has a text-only and easy-read version. The toolkits may be downloaded from www.lcint.org/?lid=3142.

Braille versions and paper copies of all versions are available on request from:

Leonard Cheshire Disability
66 South Lambeth Road
London SW8 1RL
United Kingdom
Telephone: + 44 (0)203 242 0200
Email: international@LCDisability.org.

8.3 Workshop 3 – VSO Disability Mainstreaming Handbook

VSO (Voluntary Services Overseas) is the world’s leading independent international development organization that works through volunteers in developing countries. To provide practical support to development organizations mainstreaming disability in their work, VSO drew on the contents of a successful disability program in Indonesia and Thailand and developed the “Disability Mainstreaming Handbook.” The handbook is primarily intended for VSO programs, but could be used by other development actors interested in mainstreaming disability, including NGOs, governments and donors.
8.4 Workshop 4 — Tools to promote the rights of children with disabilities

Save the Children has developed a tool to support advocacy with and for children with disabilities, using the UNCRPD and the Convention on the Rights of the Child. Called “Breaking the Barriers: A guide to using the Convention on the Rights of Persons with Disabilities with the Convention on the Rights of the Child,” it explores how the two treaties mutually reinforce the rights of children with disabilities, and need to be used together to promote the realization of their rights.

The guide is available from the Save the Children UK website at: www.savethechildren.org.uk

A shorter version of the same material is also available on the website of the Child Rights Information Network (CRIN), which can be accessed online at:
www.crin.org/resources/InfoDetail.asp?ID=15312&flag=news

For a paper copy, please contact CRIN at:
Child Rights Information Network
1 St John’s Lane
London EC1M 4AR
United Kingdom
Tel: + 44 20 7012 6866 or 67
Email: info@crin.org
Website: www.crin.org

UNICEF has produced a special issue of its journal, Innocenti Digest, called “Promoting the Rights of Children with Disabilities.” This publication covers issues related to inclusion and features case studies of successful inclusion efforts. It can be downloaded from: http://hpod.pmhcients.com/pdf/DisabledKids.pdf
8.5 Workshop 5 — Handbook for Parliamentarians on the Convention of the Rights of Persons with Disabilities

“From Exclusion to Equality: Realizing the rights of persons with disabilities” is a new handbook for members of parliaments around the world that explains in practical terms the rationale and objectives of the new Convention on the Rights of Persons with Disabilities and its Optional Protocol. It also explores the ways in which parliaments can translate the rights and principles at the core of the Convention into tangible action in their own countries.

A joint publication of the IPU (Inter-Parliamentary Union), the United Nations Department of Economic and Social Affairs, and the Office of the United Nations High Commissioner for Human Rights, the handbook is available in English, French, Spanish, Russian and Arabic.

An html version of the handbook is available online at: www.un.org/disabilities/default.asp?id=212. To download a pdf version or order a paper copy, please go to: www.ipu.org/english/handbks.htm#disabilities.

8.6 Workshop 6 — Making poverty reduction strategies inclusive

Poverty reduction strategy papers (PRSPs) are used in Africa, Asia, Eastern Europe and Latin America to form comprehensive country-based strategies for poverty reduction. The issue of disability has sometimes been left out of PRSPs, but the UNCRPD implementation process should ensure that disability is now included in all social and economic programs and strategies.

Handicap International has created “Making PRSP Inclusive,” a web-based handbook designed both for newcomers to the field and those already experienced in the disability
movement. The website provides general background information, links, resources and tools on key issues regarding PRSPs, disability and project management. It also includes useful bibliographical information and tools placed in appropriate places within the text, as well as a glossary and search tool.

The handbook is available in English, French and Portuguese and may be accessed at: www.making-prsp-inclusive.org/en/how-to-use-this-handbook.html
It is available to download at www.making-prsp-inclusive.org/en/download.html.

8.7 Workshop 7 – Inclusive education

The UN Convention on the Rights of People with Disabilities requires the development of inclusive education systems for all. A process of enabling all children to learn and participate effectively within mainstream school systems, inclusive education shifts the focus from altering disabled people to fit into society to transforming society, and the world, by changing attitudes, removing barriers and providing the right support.

Some Commonwealth countries have started this transformation within their education systems, and lessons can be learned from their experiences. Richard Rieser, Director of Disability Equality in Education, a UK NGO, and a former teacher focusing on inclusion, explains how they did it in his book Implementing Inclusive Education. The book can be used by those charged with ensuring education for all, to make certain that children with disabilities are fully included in all aspects of the education system.

To purchase a copy of the book, please go to: http://publications.thecommonwealth.org

8.8 Other toolkits, handbooks and guides

- “Equal Opportunities for All: Respecting the Rights of Persons With Disabilities” is a new publication by Disabled Peoples’ International that examines how to recognize and respect the rights of people with disabilities within the North American and Caribbean context. It can be accessed at: http://caribbean.dpi.org

- Issues relating particularly to people with intellectual disabilities are covered in “Hear Our Voices, Priority Issues for People with Intellectual Disabilities and their
Families in the implementation of the United Nations Convention on the Rights of Persons with Disabilities.” This booklet gives general information on how the UNCRPD can be applied in various situations, and provides an advocacy tool for individuals and families. The brochure is available at: http://inclusion-international.org/site_uploads/File/HearOurVoices-Priority%20Web.08.pdf

A paper copy may be obtained from:
Inclusion International
c/o The Rix Centre
University of East London,
Docklands Campus,
4-6 University Way
London E16 2RD
Tel: 44 208 223 7709
Fax: 44 208 223 7411
E-mail: info@inclusion-international.org
Website: www.inclusion-international.com

- People with intellectual disabilities and their advocates may also be interested in a publication from the Harvard Project on Disability called “We Have Human Rights, a human rights handbook for people with intellectual disabilities.” This guide supports people to learn about and recognize their rights as defined by the UNCRPD and their own countries’ laws. A pdf of the guide may be downloaded from www.hpod.org/pdf/we-have-human-rights.pdf

- “RatifyNow” was founded by lifelong disability rights advocates who worked with other advocates at the United Nations to produce the Convention on the Rights of Persons with Disabilities. The website supports global grassroots efforts to ratify the UNCRPD, and the organization’s membership is comprised of organizations and individuals who are committed to using the CRPD to protect and advance the rights of people with disabilities worldwide. It also offers a forum where people with disabilities, government officials and journalists can learn about the treaty and support grassroots efforts to promote ratification. It can be accessed at: http://ratifynow.org/2008/03/17/researching-the-crpd-on-line/

- Anyone interested in teaching others about the UNCRPD or sharing its contents with users from different backgrounds will find useful help from Handicap International, a disability and development organization working in Europe, Africa and Asia. Their website, www.handicap-international.fr/kit-pedagogique/indexen.html, offers visual aids and documents that can be downloaded in French and English.

- “Invisible People, A practical guide for journalists on how to include persons with disabilities” was produced by the African Decade of Persons with Disabilities,
a project of the African Union. This interesting handbook for journalists covers a range of issues relating to how disability is portrayed in the media. Its goal is to help journalists recognize and overcome stereotypes in the way that they think about, write about, speak on and film disability issues. To access an online copy, go to: www.africandecade.org. For a paper copy, please write to:

The African Decade
PO BOX 587
Cape Town 8000
South Africa

• “It’s About Ability, an explanation of the Convention on the Rights of Persons with Disabilities” was published by UNICEF to explain the Convention to children. It may be used by children, teachers, parents and others to help convey a human rights based understanding of disability, and how children with disabilities are entitled to the same treatment as non-disabled children. A pdf version in English, French or Spanish may be accessed at: www.unicef.org/publications

To order a free paper copy in English, French or Spanish, please email pubdoc@unicef.org or write to:

Distribution Unit
Division of Communication
UNICEF
3 United Nations Plaza
New York, NY 10017
USA
Please provide full details, including the title and language, and your address.
Please allow 3 to 4 weeks for delivery to developing countries.

• UNICEF has also created a version of the UNCRPD in child-friendly language. This may be downloaded in English on: www.unicef.org/Child_friendly_CRPD.doc

• The Convention on the Rights of Persons with Disabilities and its Optional Protocol are serviced by a joint Secretariat, based both in the United Nations Department of Economic and Social Affairs (DESA) in New York, and the Office of the High Commissioner for Human Rights (OHCHR) in Geneva. Their website, www.un.org/disabilities, provides a full list of countries that have signed and ratified the Convention and its Optional Protocols, as well as other information relevant to the Convention. The full text of the UNCRPD is available in more than ten languages on the site.
9. Conclusion: because I decided

“I hope this meeting of minds here in Addis will crystallize our resolve to communicate our compelling new agenda to the chattering classes of the world, to shake off the comfortable padding that insulates us from the pain and the injustice felt by those in real need. We have the hands, the hearts and, especially after this Convention, we have the mindset and the passion. And as we congregate here at the very birthplace of the human race, we lift our sightless eyes, we focus our dormant ears and we flex our disobedient legs, and with every fiber of our being we say with one united voice, oh yes, we can bring about a change.”

– Amar Latif, Founder and Director, Traveleyes UK

“Vision is the act of seeing the invisible.”

– Ephraim Segone, Young Voices Representative, South Africa

When Amar Latif, one of the conference’s closing panel speakers, became blind at the age of 20, he realized that disability was accompanied “by a couple of nasty sidekicks: inequality and lack of access.” Then he adopted what he called a “fight back strategy” in which he “began a new approach: to think in terms of what’s possible despite disability.” Now, he says, “I feel a growing responsibility, not just to make demands for action, but also to roll up my sleeves and get down to being part of the action.”

Mr. Latif’s words crystallize the resolve felt and strengthened at this conference: with the impetus of the new UN Convention, the time for action on disability, development and full human rights is upon us. “Finally,” added Ephraim Segone, the Young Voices closing speaker, “what we have begun in this conference becomes important when implemented after the conference, as it is outside where lives are at stake.”

In the words of Alexander Phiri, another closing speaker, “what are you going to do from here? The solution that I am proposing is that when you get back, before you expect the UN, before you expect our countries to do something about the Convention, why don’t you do it yourself? Do something about it, you can.”

This action, at its best, will both contribute to and support implementation. At this stage, said the closing speaker from UNECA, Thokozile Ruzvidzo, “The conference does not call for us to revisit the Convention. It does not call for changes in the Convention because... the Convention is solid. What it needs is implementation. So what the call for action calls for is: ratification, awareness raising, implementation, capacity building. It also calls for monitoring, it calls for partnership of governments, civil society, the UN agencies and the different institutions, not necessarily just institutions that are working...
on disability issues, because the issue of disability cuts across all the different areas that you are involved in.”

Young people have a particularly exciting role to play in this action, said Ephraim Segone. As the future of the disability movement, they can pressure governments to sign, ratify and implement the Convention. “If doors are not open for us,” said Mr. Segone, “fortunatley we are still energetic and young, we can still take them down. We now have a call for action from this conference,” he said, “which is not called a ‘call for discussion’.”

Mr. Segone went on to say that we also need to enhance our efforts on awareness raising, especially in schools where accessibility and reasonable accommodation are not considered, and where teachers don’t know how to handle learners with disabilities. “We need to fight the good fight,” he continued, “not with fists and physical weapons, but through teaching, integrating and upholding the positive attitudes we have adopted to conquer the challenges brought by life with disability.”

Unity was another important rallying cry for Mr. Segone. Collective effort can accomplish more than any one individual, and unity, he asserted, has a power of its own. The conference itself was created by collective effort, and harnessing this will help implement both the Convention and the fresh thinking embodied in both it and the conference. “We have what it takes to turn things around. We need to be the change that we want to see. We are the voices that can speak on behalf of our brothers and sisters who travel with us in the same boat, one that is threatened by waves of ignorance and discrimination. We are the vessels overflowing, vessels filled with passion, determination, drive and action, and we have an assignment waiting for us. This road may not be an easy one, but I am confident that together we shall stand. I plead with all of you, brothers and sisters, to stand and be the voice of change.”

This can extend to partnerships between people with disabilities and organizations such as the UN, non-governmental organizations and other institutions, which can be catalysts for this kind of action, added Mr. Phiri. In addition to integrating disability into their programs, they can employ disabled people as consultants, on staff and as volunteers.

To forge this collective action requires individuals to work together. Amar Latif, for example, auditioned for a play in which the other actors were not disabled. When the director told him that his blindness meant he couldn’t possibly cope, “I decided he was wrong,” said Mr. Latif, and he not only got the part, but has worked as an actor since. Later, having experienced problems with air tour operators, he continued, “I decided to become one.”

For him, “The important phrase in all of this is I decided’. The decision, like the responsibility, was mine. Fail or succeed, the buck can only stop with me. The crucial factor is always self-motivation. Self-motivation confers empowerment and empowerment confers
independence. For me, as a blind person, independence is my most treasured possession and independence demands equal access... And, we don't always need to follow in the footsteps of others. Disabled people can be the trailblazers in their own right.”

Adding her voice to this call, Thokozile Ruzvidzo told of her determination to bring the Convention to life by making the UNECA Conference Center truly accessible, inspired by the many trailblazers who attended this conference. “Your poetry and your humor,” she told Mr. Latif, “have challenged us to make the speakers’ podium, up to now inaccessible to wheelchair users, accessible to everyone.”

In the words of Mr. Latif, “We’ve all come together here, some of us blind, some of us sighted, some of us disabled and some of us able bodied, but we all share a joint passion and a united vision. We’ve come here from every corner of our incredible but frustratingly unequal world. We’ve come together to this breathtaking landmass that is mighty Africa. More specifically, we’ve come to the beating heart of this magnificent continent and even more specifically still, to this land that history tells us was almost certainly the birthplace of humanity.”

To those who were there and to those reading this report, may this conference be the birthplace of concerted action on implementing the UNCRPD and achieving full human rights for people with disabilities.
Annex 1: Addis Ababa call for action

Implementing the UNCRPD: our shared challenge

UN Convention of the Rights of Persons with Disabilities: a call for action on poverty, discrimination and lack of access

Addis Ababa, Ethiopia
19–22 May 2008

We, the 500 participants from 58 Countries, in this conference jointly organized by the United Nations Economic Commission for Africa and Leonard Cheshire Disability,

Recall that the United Nations Convention on the Rights of Persons with Disabilities came into force on May 3rd 2008, and that the Convention marks a major milestone in recognizing the human rights of persons with disabilities and their roles as active members of society and in development (Article 4.3 UNCRPD),

Cognizant that the Convention has been adopted by the United Nations General Assembly,

Recognize the efforts of the international community including the United Nations System in focusing global efforts on the Convention,

Understand that by ratifying the Convention, Member States are committed to enact laws, adopt policy measures, and take all necessary steps to implement the provisions of the Convention,

Recommend that in order to implement and monitor progress, Member States, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels (Article 33 UNCRPD),

Urge Member States, in accordance with legal and administrative systems, to maintain, strengthen, designate or establish a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present convention, for which Member States shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights,
Recommend that civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the implementation and monitoring process,

Recall that Member States recognize the importance of international cooperation and its promotion in support of national efforts for the realization of the purpose and objectives of the UNCRPD (Article 32),

Adopt this Call for action to request governments, the United Nations System, donors, international financial institutions, disabled people’s organizations, civil society, private sector, trade unions, and media, to:

1. Build capacity and empower all stakeholders to participate in the implementation and monitoring of the UNCRPD, by:
   a. Building awareness among persons with disabilities of their rights under the UN Convention and how they can be made a reality;
   b. Building capacity, internally and among other stakeholders, to deliver the obligations under the Convention; and
   c. Ensuring that persons with disabilities, disabled people’s organizations and parents and associations of parents of children with disabilities are involved at all stages of implementation, monitoring and review of the UNCRPD, and can seek individual redress under the UNCRPD.

2. Support the establishment of a structure and strategies to implement the UNCRPD, through the:
   a. Establishment of a United Nations agency specifically for the implementation of the UNCRPD.
   b. Strengthening of international, national and regional partnerships and cooperation between stakeholders to deliver the UNCRPD;
   c. Introduction of a transparent implementation strategy for the UNCRPD that has a practical impact on society;
   d. Support of the United Nations System, agencies and programs and others in establishing a systematic and consistent measurement of delivery of the UNCRPD;
   e. Provision of adequate resources for the research, data and statistics needed for successful implementation; and
   f. Commitment to the necessary and adequate resources to implement the UNCRPD;

3. Commit to promoting the design and development of effective national legislation and policies to implement the UNCRPD by:
   a. Ratifying the Convention and its optional protocol without reservation at the earliest possible time;
   b. Introducing and enforcing legislation implementing the UNCRPD, especially measures which prevent and address discrimination based on disability;
c. Creating development programs that are genuinely inclusive;

d. Achieving full access to quality education and health care, decent work, basic services, transport, ICT, the built physical environment, justice, relationships and family life for all citizens – all means all;

e. Assessing the implications for persons with disabilities in the design and delivery of legislation, policies or programs, in all areas and at all levels; and

f. Recognizing the centrality of the link between disability and poverty, without which the Millennium Development Goals will not be achieved.

The participants believe that this can only be achieved by coordinated action among all stakeholders, as all of these issues are inter-related and none can be delivered in isolation.

There is great urgency. The time for **action is now**.
Annex 2: The Young Voices participants

Botswana  Mr. Otladisa Manthe
Brazil    Ms. Beatriz Lonskis Lopez
China     Mr. He Zhixiong
Ethiopia  Mr. Mekonnen Temesgen
Guyana    Ms. Fidelle Pitt
India     Ms. Yellamma Gangadhar
Kenya     Mr. Gurston Opar
Liberia   Ms. Daintowon D. Pay-bayee
Malaysia  Mr. Mahmud Arif Karkhi Abukhudairi
Namibia   Ms. Nicolette Pieters
The Philippines  Ms. Carla dela Cruz
Sierra Leone  Mr. Mohamed Saidu Kamara
South Africa  Mr. Ephraim Segone
Sri Lanka    Mr. Ranjana Chandralal
Sudan      Mr. Bosco Wani
Swaziland  Mr. Bongani Simelane
Uganda     Ms. Luba Munaba
Zimbabwe  Mr. Shedreck Ngocho

Ms. Naomi McAdam, an observer from the Commonwealth Disabled Person’s Youth Forum, also attended the Young Voices activities.
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