Status Report on Poverty and Disability in the Americas

Voices from the Americas

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The Status Report on Poverty and Disability in the Americas contains the results of research provided by people who have a disability, families, organizations and associations of people with disabilities and their families, governments and professionals from different sectors. In addition this report reflects the views and analysis of the participants of the First Inter-American Forum on Poverty and Disability (Managua, August, 2004). Inclusion International and Inclusion Inter-Americana gratefully acknowledge all of the individuals who contributed to this important study providing information, participating in and facilitating the focus groups, generating the country reports, developing presentations and preparing the document. We would like to especially thank all the people with disability and their families who participated and shared their experiences so generously.

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<td>Assistencias Filantrapicas y FENAPAES</td>
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<td>El. Parv. Marcela Santos J.</td>
<td>Coordinadora Centro de Recursos</td>
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<th>FAMILIES TELL US</th>
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<tr>
<td>1. Eradicate Extreme Poverty For People with Disabilities and their Families</td>
<td>The World Bank estimates that people with disabilities account for as many as one in five of the world’s poorest people, suggesting that 260 million (43%) of the estimated 1.3 billion people worldwide living on less than $1 per day have a disability.</td>
<td>Due to lack of inclusive education, basic services and health care, people with disabilities are prevented from integrating into society. It is very difficult to gain employment with a lack of training and facing employer discrimination. Without a job or an education people with disabilities cannot break the cycle of poverty.</td>
<td>Processes to mainstream disability in poverty reduction strategies need to involve civil society organizations (DPOs and family associations). This will require tools and resources to support the participation of these groups in PRSP processes for example.</td>
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<td>2. Achieve Inclusive Education</td>
<td>Recent UNESCO studies suggest the highest incidence and prevalence of disabilities occur in the poorest areas, where less than 2% of children with disabilities attend school.</td>
<td>The systematic discrimination and segregation of children with disabilities extends to the classroom where teachers have not been properly trained, and inadequate resources are in place to develop inclusive education for all children.</td>
<td>Education reform processes must include consideration of marginalized groups in society. The majority of the population of students in many developing countries can be considered part of a marginalized group. This means education policy MUST address the needs of a wide range of learners. Inclusive Education is the answer.</td>
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<td>3. Promote Gender Equality for Women with Disabilities</td>
<td>UNICEF estimates that only around 1% of girls with disabilities are literate. Women with disabilities are among the world’s most disadvantaged populations.</td>
<td>Responsibility of care giving falls disproportionately on mothers or female siblings resulting in even fewer opportunities for female family members to gain employment or complete schooling.</td>
<td>Strategies to address gender equality for women with disabilities must be developed in the context of mainstream economic and social policy. Many strategies to address women’s issues in the development context have not been successful in understanding the gender implications for policy options. Knowledge of the key development issues for women with disabilities and mothers of children with disabilities would significantly impact on policy alternatives and programmes in health, employment, education etc.</td>
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<td>4. Reduce the Mortality of Children with Disability</td>
<td>The lives of infants with disabilities are often so undervalued that they are not cared for or fed as families struggle with meager resources.</td>
<td>Mortality for children with disabilities may be as high as 80% in countries where under five mortality as a whole has decreased to below 20%.</td>
<td>Data on child mortality must begin to be disaggregated in order to track health indicators and interventions for children with disabilities. Within vaccines and post-natal interventions, families and community workers must be educated to monitor access to these services for children with disabilities.</td>
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<td>5. Achieve the Rights of Children and Families</td>
<td>Families report that time to build social networks and support circles, friendships, get involved in their community are consumed by need to just get by, resulting in fewer mechanisms for support and limited social capital.</td>
<td>It is estimated that only 2% of people with disabilities in developing countries have access to rehabilitation and appropriate basic services.</td>
<td>Signatories to the UN Convention on the Rights of the Child (UNCRC) have committed to develop National Action Plans for the implementation of the UNCRC. These action plans must include strategies to address the needs and rights of children with disabilities.</td>
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<td>6. Combat HIV/AIDS</td>
<td>The World Bank preformed an international survey which concluded that HIV/AIDS is a significant and almost wholly unrecognized problem among disabled populations worldwide. While all individuals with disability are at risk for HIV infection, subgroups within the disabled population—most notably women with disability, disabled members of ethnic and minority communities, disabled adolescents and disabled individuals who live in institutions, are at especially increased risk.</td>
<td>Extreme poverty and social sanctions against marrying a disabled person mean that they are likely to become involved in a series of unstable relationships. Disabled woman are often a target for rape, which puts them at risk. There are almost no sexual education programs targeted towards people with disabilities. The global literacy rate for people with disabilities is estimated to be only 3%, thus making sexual education and HIV/AIDS information difficult to disseminate, especially for those who are deaf and/or blind.</td>
<td>HIV/AIDS education and drug programmes must target vulnerable populations including people with disabilities: This will require strategies for HIV/AIDS strategies to seek out support from disability groups and for disability and family based organizations to seek out collaborative strategies with governments and HIV/AIDS programmes.</td>
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<tr>
<td>7. Ensure Environmental Sustainability</td>
<td>UN statistics state that about 20% of all disabilities are caused by malnutrition and over 10% are caused by infectious diseases</td>
<td>In many makeshift communities and shanty towns there is a disproportionate number of people with disabilities. They live their because they are unable to participate as individuals in economic activities or because their families have been unable to meet both their disability needs and the basic needs of the family for food and shelter. Poor nutrition, dangerous working and living conditions, limited access to vaccination programmes, and to health &amp; maternity care, poor hygiene, bad sanitation, inadequate information about the causes of impairments, war and conflict, and natural disasters all cause disability.</td>
<td>Strategies targeted at homeless populations must include targeted programmes to address the needs of people who have a disability and their families. These strategies should take into account the barriers to economic, social ad political participation that exist in the mainstream communities of that country.</td>
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## SUMMARY OF FINDINGS AND RECOMMENDATIONS

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<th>MILLENNIUM DEVELOPMENT GOAL</th>
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<th>POLICY ISSUES</th>
<th>RECOMMENDATIONS</th>
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<td>8. Develop a Global Partnership for Development</td>
<td>Recent estimates indicate that there are approximately 450 million people with disabilities living in the developing world. Approximately 30-40% of households care for a member with a disability</td>
<td>The exclusion and systemic undervaluing of people with disabilities perpetuates a cycle of poverty and isolation. Unless disabled people are brought into the development mainstream by creating global partnerships for advocacy and development it will be impossible to achieve full human and economic rights.</td>
<td>Multilateral investment strategies to address inequalities among nations must also take into account inequalities within sovereign nations. Free trade and the removal of trade barriers will generate wealth within nations but the eradication of poverty requires policies to promote economic and social participation of all groups in society.</td>
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INTRODUCTION

Achieving the Millennium Development Goals depends on our collective ability as governments, civil society, international agencies and individual citizens to understand the root causes of exclusion faced by the world’s poorest. People who have a disability are among the poorest of the world’s poor and their exclusion from education, the workplace and all aspects of community life and society is systemic. The purpose of this study is threefold: to draw attention to the extreme and systemic poverty faced by people with disabilities in Latin America and the Caribbean; to better understand the relationship between disability and poverty by drawing from the knowledge and experiences of people who have a disability and their families who live in poverty; and to set some policy directions for poverty reduction initiatives and disability programmes in the region.

Increasingly governments and international financial institutions are recognizing that real knowledge about how to address the sources and underlying causes of poverty lies with people and communities at the local level who live in poverty. The World Bank’s Voices of the Poor research is based on an understanding that the real experts on poverty are people who live in poverty. Likewise people who have a disability and their families are the experts on disability and the factors affecting their inclusion or exclusion. In order to ensure that people who have a disability are considered in strategies and investments to meet the MDG’s, Inclusion International has designed a global initiative to ‘Link local knowledge to global change’, bringing the voices of people who have a disability and their families who are also poor to the tables and processes where decisions are made.

This study is the first of four regional studies in a three-year initiative by Inclusion International to draw global attention to the conditions of poverty and their impact on the lives of people who have a disability and their families. The initiative will support people with disabilities, their families, associations and networks to come together in each of the four participating regions (the Americas, Africa and the Indian Ocean, Europe and the Middle East) to develop strategies to identify the causes of poverty and address those conditions. With the financial support of the Norwegian Association for Persons with Developmental Disabilities (NFU), member of Inclusion International. Inclusion International is working with each of its regional associations to host a regional forum at which the initial research findings will be used as a basis for developing strategies and implications for policy in different sectors.

Part I of this report, Understanding Inclusion, was developed through a participatory research process that took place prior to the First Inter-American Forum on Poverty and Disability in the Americas; Towards Inclusion (August 11th-13th, 2004, Managua, Nicaragua). Part II, Strategies and Policy Implications was developed to reflect the analysis and strategies that emerged from the Forum. Similar documents will be prepared in other regions of the world culminating in the release of a Global Status Report on Poverty and Disability at the Inclusion International World Congress in Acapulco, Mexico in 2006.
PERSPECTIVES ON POVERTY AND DISABILITY

By DIANE RICHLER, President, Inclusion International

An Address to the Inter-American Forum on Poverty and Disability

To ensure social well-being for all people, societies have to be based on justice, equality, equity, inclusion and interdependence, and recognize and accept diversity. Societies must also consider their members, above all, as persons, and assure their dignity, rights, self-determination, full access to social resources and the opportunity to contribute to community life.”

~Declaration of Managua

The Declaration of Managua pointed to the fact that often, the policies that were erecting barriers for people with a disability were being developed far beyond national borders, and that if people with disabilities and their families wanted to make a difference, they were going to have to try to influence those policies of donors and multi-lateral institutions.

In both wealthier and poorer countries, people with a disability pay an economic price. Excluded from education, people with disabilities have less opportunity to earn a decent living. Families pay an economic price too, as often a woman of the household – mother, sister or grandmother must sacrifice work or education to care for a member who has a disability. The extra costs of disability – medicine, health care, special diets, and need for adapted transportation – add to the economic costs of disability. In Canada, an analysis of the tax system showed that families of people with a disability were not being adequately compensated for the extra costs of disability.

The amount of time and resources required to care for a family member with a disability often means that families pay a social and political price as well. Socially, in all corners of the Americas, people with a disability and their families report a feeling of isolation. This comes from negative stigma still associated with disability coupled with the difficulty for both people with a disability and their families to have the free time necessary to build social networks. Likewise, individuals and families lack the time to engage actively in political activities, and therefore have little opportunity to influence the policies that so affect their lives.

Placing the cost of disability so disproportionately on the shoulders of persons with a disability and their families has amounted to a privatization of disability. Communities and governments have felt no responsibility to deal with the challenges facing people with a disability and their families and therefore have not seen disability as a matter of public policy. In the majority of cases in Latin America and the Caribbean, when services for people with a disability do exist, they are funded by external donors and are little more than charity.
The disability rights movement was an offspring of the human rights movement that emerged after World War II. The civil rights movement inspired people with a disability to see their own situation from a rights perspective.

But unfortunately, while governments and multi-lateral institutions have begun to recognize the discrimination against people with disabilities (for example, 20 countries in the Americas have ratified the Inter-American Convention to Eliminate All Forms of Discrimination Against Persons with a Disability) little has changed in fact. As one of the country reports prepared for this seminar pointed out, if all of the laws currently on the books in Latin America and the Caribbean were implemented, most of the current challenges facing people with a disability and their families would be overcome.

So why hasn’t that happened? Why despite numerous human rights commitments at the national, regional and global level specifically outlawing discrimination on the basis of disability do people with a disability continue to be among the poorest of the poor? The answer is all too simple: there has been no investment to translate rights into reality. In order to change that pattern, we need to understand how current investments are being made and determine how people with a disability can start to benefit from the investments being made.

To do that, it is helpful to understand the context of current investment strategies at the global and regional levels.

According to UNDP, in 2003, 43.9% of the population of the Latin America-Caribbean region were poor – living on less than $2 a day, and 19.4% were extremely poor – living on less than $1 a day. The region also has the highest level of inequality in the world, with the wealthiest 10% earning 30 times the income of the poorest 10%. In 2000, the governments of the world and UN agencies had to admit that their strategies for improving living conditions for the poor were not working. The rich were getting richer, but none of their gains were trickling down to the poor as had been predicted. So, the poor were getting poorer.

In order to consolidate efforts to reduce poverty, in 2000 the UN adopted the Millennium Development Goals, a series of 8 time-limited targets with measurable results in order to focus on the major perceived roots of poverty. In synthesis, these Millennium Development Goals are:

1. Eradicate extreme poverty and hunger
2. Achieve universal primary education
3. Promote gender equality and empower women
4. Reduce child mortality
5. Improve maternal health
6. Combat HIV/AIDS, malaria and other diseases
7. Ensure environmental sustainability
8. Develop a global partnership for development
As the major multi-lateral institutions like the World Bank, the Inter-American Development Bank, UN agencies and governments have attempted to focus their efforts on poverty reduction rather than simply on economic growth, there has been increased recognition of the links between poverty and disability — that poverty causes disability and disability causes poverty. However, there has not yet been a corresponding shift in investment strategies. One reason for this is the lag between the conceptualization of poverty from a purely monetary perspective to the development of newer definitions that focus on capability, social exclusion, or participatory approaches.

Researchers at the University of Oxford have been helpful in laying out four different frameworks for defining poverty. They show that how one thinks about poverty then affects what one measures, and what one tries to change. (Ruggeri Laderchi, Saith and Stewart, 2003)

The most common way of defining poverty is the monetary approach — measuring income and what that will purchase in the market. Because of the well-developed and well-entrenched measures of monetary poverty, it continues to dominate how investment strategies are developed and implemented.

Another framework for measuring poverty has been developed by the Nobel Prize winning economist, Amartya Sen. Sen’s capability approach places greater emphasis on the freedom to direct one’s own life. Therefore, this approach considers a wider range of causes of poverty, and subsequently, a wider range of policy options than a purely monetary approach. This is of paramount importance to persons with a disability.

A third framework for understanding poverty is the participatory approach. This method relies on those affected to subjectively interpret what matters to them in an attempt to give them control over their lives. It is this approach that has influenced the development of documents like the World Bank’s “Voices of the Poor”.

The concept of social exclusion focuses on the participation of individuals in society. This is also an extremely important concept for persons with a disability. Interestingly, the concept of social exclusion emerged in Europe after the Second World War as an attempt to deal with the economic inequalities that were seen as the root of armed conflict. It is worth noting that as the European Union has prepared for the accession of new members over the past several years they have invested heavily in social inclusion in an attempt to minimize the risk of inequality leading to social unrest in the future.

Policy documents in the hemisphere increasingly reflect this multi-dimensional view of poverty, but mechanisms for ensuring their application in the review and evaluation of loans and other investments are lacking. The framework for evaluation continues to be based more on outcomes and measures that reflect a monetary approach.

So how can we change the current situation? How can we help to highlight the poverty facing people with a disability and their families and influence investments to address the situation?
Because the Millennium Development Goals have become such an important framework for investment in development, Inclusion International has studied their implication for people with a disability and their families.

II has said that because of the number of people with a disability in the Americas who are poor, and the impact of their poverty, the Millennium Development Goals cannot be reached if people with a disability and their families are ignored. And for the first time, donors are taking us seriously because they recognize that their own goals will not be met unless the poverty of people with a disability is addressed.

It is worth emphasizing that the II approach to tackling the Millennium Development Goals for people with a disability is to engage with a large number of actors in the process. We recognize the role of individuals and families to speak out on their own behalf and articulate their needs and priorities. But we also value the role of professionals, of governments and of donors and recognize the need to work together. Through a joint process of Knowledge & Data Collection, Resource Development & Knowledge Sharing and Policy Engagement, we are attempting to shift investments so that the poverty of people with a disability and their families will be addressed.

The UNDP has recently completed a major study on democracy in the hemisphere. The report comes to a number of important conclusions. It recognizes that:

- Poverty and inequality of the region are crucial problems and are major threats to democracy
- Full citizenship is comprised of political, civil and social citizenship
- Political, civil and social citizenship are not integrated in the region; only 17% of the poor exercise their civil citizenship
- The process of democratization in Latin America has focused on political citizenship and not adequately on social citizenship
- If democracy is to flourish and survive, there has to be voice and power to the poor
- “Democratic development is closely linked to the search for greater social equality, the fight against poverty and the expansion of citizens’ rights”
- States have limited resources to meet social needs and their power is restricted by internal and external forces

Finally, the document recognizes citizen engagement in the implementation of the Millennium Development Goals as a potential major contributor to a process of democratization in the region. In effect it validates II’s focus on the Millennium Development Goals and our attempt to influence policy as a contribution to the democratic process.

Robert Putnam, the Harvard scholar, has written a lot about democracy, economic development and social capital. In effect, he shows that when civil society flourishes, so does democracy and the economy. More recently, he has focused on social capital, the “social networks, norms of reciprocity,
mutual assistance and trustworthiness” that strengthens communities, supports democratization, and creates the conditions for economic growth. In fact, when people with disabilities are excluded from their communities, there is a draining of social capital. The main losers are the people with disabilities themselves, and their families. But communities are losers too. Communities are denied the opportunity to build robust social capital when families are left with the full responsibility for their disabled member or when segregated programs keep them out of the mainstream – and communities are thus denied the opportunity to develop ways to respond to diversity and to benefit from all their members.

Putnam makes some interesting comments on investment. He shows that often what build’s social capital is not only investing in the perceived problem, but also in strategies designed to build the social capital that can address the problem. So for example, he values the time that volunteers in a school program have to socialize and build friendships and identifies how that contributes directly to improving the quality of education. Providing volunteers with extra space to meet, with meals and coffee allow the socialization to take place. He acknowledges that many funders see such investments as superfluous, and are loathe to finance them because they do not appear to address the primary problem.

Putnam’s work on social capital brings us back to the different frameworks for understanding poverty, and the subsequent design of poverty reduction strategies. As long as traditional economic measures are the primary means for allocating resources, people with a disability and their families will remain among the poorest of the poor. But if we can work with those promoting newer models – capability, social inclusion and participatory – then we can address the systemic roots of the links between poverty and disability, and contribute to the further democratization of the Americas in the process.
Part One

Understanding Exclusion

1. REGIONAL CONTEXT

The link between poverty and disability in the Americas is clearly evidenced in existing data and in the experiences of people with disabilities and their families. Yet research and public policy in poverty has largely excluded consideration of people with disabilities and research and public policy designed to promote the inclusion of people with disabilities has often ignored the impact of poverty.

- People with disabilities in the Americas have higher unemployment rates and lower earnings than the non-disabled – (ILO) ¹
- Available data shows that in Brazil, disabled workers earn 45% less than non-disabled workers.²
- In Costa Rica, where the definition of disability is wider, the difference is 11.5%. And yet, research indicates that when people with disabilities can find jobs, they take fewer days off and tend to stay with employers longer.³
- In El Salvador, where approximately 98% of the people with disabilities are unemployed, technology is beginning to open up greater economic opportunities.⁴
- According to the Inter-American Development Bank (IDB, 1999) approximately 5 million Central Americans are disabled. Half are of working age, but most can’t find jobs. They are the poorest of the poor.
- A study of Colombia showed that one more day of disability decreased male rural earnings by 33% and female by 13%, that having a disability in a given month decreased the earnings of an urban male by 28% and by 14% for an urban female.⁵

⁵ Productivity and Household Investment in Health - The Case of Colombia by Rocio Ribero1 and Jairo Nuñez2, 3 New Haven, January 29, 1999
1.1 Poverty Reduction in the Americas

Poverty reduction has become the focus of international development efforts. Since 2000 when world leaders adopted the Millennium Development Goals, there has been an increased effort to coordinate development activities to this end. Within the Americas, the major multi-lateral institutions and donors have made poverty reduction a priority. The World Bank, which in 2003 had $20 billion invested in projects in Latin American and Caribbean (LAC) countries, has as its mission “to fight poverty and improve the living standards of people in the developing world.” Likewise, the two main objectives of the Inter-American Development Bank (IDB) are poverty reduction and social equity and environmentally sustainable growth. Its mandate requires that half of its operation and 40% of its resources be devoted to social programs that target the poor. According to the World Bank, one quarter of the population of the LAC region lives in poverty (defined as living on under $2 a day) and 40% of them are extremely poor (living on less that 1$ a day). While the World Bank acknowledges that people with a disability are among the poorest of the poor, traditionally investments in poverty reduction have not been directed at people with disabilities.

Low-income countries can seek debt relief from the World Bank and International Monetary Fund, through a comprehensive strategy that requires the drafting of a national Poverty Reduction Strategy Paper (PRSP) that must reflect and try to reform a country’s macroeconomic, structural and social policies and programs to promote growth and reduce poverty. The PRSP process is based on several core principles. They must be country-driven and involve broad-based participation by civil society and the private sector in all operational steps. This process offers local civil society organizations a way to link their local activities to national and global initiatives all aimed at achieving the same goal: poverty reduction.

In the LAC region, there are five countries participating in the PRSP process: Dominica, Guyana, Honduras, Nicaragua and Bolivia. While all PRSPs mention the vulnerability of people with disabilities, only in Honduras do proposed investments correspond to the challenges identified in the documents.

Mentioning disability in the PRSP is important because that then serves as the basis for the Country Assistance Strategy (CAS) developed by the Bank. All lending, grants, credits, etc. are supposed to flow from the strategy mapped out in this document. If disability is not in the PRSP it is not included in the CAS, and it becomes much harder to get disability issues included in subsequent projects.

The World Bank has had a focus on disability since 1998, and that focus intensified with the creation of a Disability and Development Group in 2002. This group is playing an active role in developing better statistics on persons with disabilities and promoting the mainstreaming of disability and development, particularly in Education for All and in infrastructure programs. Within the LAC region, the

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1 Bolivia’s PRSP cites persons with disabilities among those most affected by poverty; Nicaragua calls persons with disabilities a “permanently vulnerable group”; Guyana identifies the need to mainstream disability in poverty programs; and Honduras calls for specific policy measures and projects to provide assistance to poor persons with disabilities.
appointment of an Advisor on Disability and Development has enabled the Bank to assist governments to include children with disabilities in educational reform. Significantly, the LAC region has also created a disability sentinel to screen all projects being reviewed for financing to enhance the benefits to people with disabilities.

The PRSP sourcebook provided by the World Bank has been criticized for continuing to espouse a limited social protection approach that portrays people with disabilities as ‘welfare cases.’ According to the ILO “The Sourcebook has negatively influenced a number of (I) PRSPs, including those that have tried to include measures concerning disability and disabled persons.” PRSP policies that attempt to address the concerns of people with disabilities focus on provision of services and not at all on creating inclusive structures. As a result none of the evaluations by the World Bank and IMF of the PRSPs in the Americas mention people with disabilities or offer any constructive critique of inappropriate policies regarding people with disabilities.

The IDB has incorporated disability in its unit on Social Inclusion, but it does not as yet have a systematic way to ensure consideration of persons with a disability in its investments.

Poverty reduction is also a focus of the UNDP. The 2004 World Human Development Report defines disability but makes no other mention of it, nor was there a reference to disability in the majority of the national Human Development Reports from the LAC region reviewed for this study.

Gradually, documents such as the PRSPs, multi-lateral and national policy papers are beginning to acknowledge the vulnerability and poverty of persons with a disability, but there has not yet been a corresponding shift in investment strategies. This appears to be because of a lag between the conceptualization of poverty from a purely monetary perspective to the development of newer definitions that focus on capability, social exclusion, or participatory approaches (Ruggeri Laderchi, Saith and Stewart, 2003). Because of the well-developed and well-entrenched measures of monetary poverty, it continues to dominate how investment strategies are developed and implemented. So, while for example the World Bank has begun to create reports that reflect “the voices of the poor”, the framework used for evaluating PRSPs and specific loan requests continue to be based on more outcomes and measures that reflect a monetary approach.

Sen’s capability approach (1985, 1999) places greater emphasis on the freedom to direct one’s own life. This is of paramount importance to persons with a disability. The concept of social exclusion focuses on the participation of individuals in society. This is also an extremely important concept for persons with a disability. Participatory poverty assessments recognize the subjective nature of the poverty experience and the agency of people in their own lives. Policy documents in the hemisphere increasingly reflect this multi-dimensional view of poverty, but mechanisms for ensuring their application in the review and evaluation of loans and other investments are lacking.

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2. FAMILY PERSPECTIVES

2.1 Hearing Their Voices

This section is written, based on the information presented by the facilitators of the focus groups that took place in seven countries in the Americas. (Translated from Spanish)

According to the World Bank reports on poverty, to the UNDP Development Program, to the UN Millennium Development Goals, there is an urgent need to learn from people who face poverty in order to try to transform their lives.

Studies show that for people who live in poverty there is a need not only to improve opportunities to generate income and to satisfy their basic needs; but also to recognize their vulnerability when confronting the crisis that threaten their sustenance and/or survival. There is a need to improve the social and political context in which they live to address discrimination, social barriers, conflicts, exclusion, service delivery, linguistic barrier and lack of access to their minimum rights.

What happens when a member with a disability is added to the families in this complex and multi-dimensional context?

Experiences shows how people with disabilities and their families, from all over the Americas, face various adverse situations on a daily basis, where they have to search for alternative solutions to the different challenges that they are presented with, so that they can offer a better quality of life for their sons and daughters.

Studies focused on families who have a member with a disability have identified many of the source issues that emerge in poverty studies. Both of these two groups have limited access to education. The reason for this is on the one hand, that they do not have the economic resources to send their children to school, and on the other, that the schools do not accept them due to the fact that they have a disability (World Bank’s facts show that only 2% of the population with disabilities attends to schools in development countries).

With this document, Inclusion International has the intention of including the perspective of the families that face poverty challenges and that have a member with a disability, so that they can express what it signifies to live in the dualistic realm of poverty and disability.

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3 Focus Group countries included: Bolivia, Colombia, Chile, Ecuador, El Salvador, Guatemala, and Nicaragua.
2.2 Focus Groups

The following questions were asked to the families: What are the challenges? What motivates a family with scarce resources to search for alternatives for solutions, in spite of the problem of lack of resources? What situations have they overcome? What would make their life easier? Around their everyday life, what tools do they have to use? Which ideas have they thought about?, What do they expect from government and public Institutions?, and what else are they willing to do for their sons and daughters?

A group of families with a disabled member that were considered to live in poverty were selected. These families generated focus groups in seven countries, in order to express their challenges and possibilities. The objective is to try to understand how the discrimination, social barriers, lack of access to services, and the little information on their rights, affect or not, in a direct way, the capacity that they have to take advantage of their potential, and if they create a lack of sense of representation and power.

In order to offer a context on the selected families, the information imparted by focus groups which describes the characteristics of the communities that participated, is provided:

“Families that are in danger of abandoning their members who has a disability, or those who are subjected to psycho-social risk factors and the violation of their rights; who belong to lower level on the socio-economic classification; the majority, with no academic training and without a job, dedicated to the informal economy or to begging.” Located in deprived outskirts sectors of the city of Medellin, in the department of Antioquia (Colombia).

Family profiles, one-parent (mothers) homes with absent fathers, with an average size of four to eight members; without schooling, unemployed or dedicated to the informal economy, with dissatisfaction of their basic necessities, in high risk of being abandoned and with little protection.

Their stories are usually framed in violent situations, victims of mistreatment, discrimination or social rejection, with highly vulnerable fundamental rights, and with the presence of other risks such as the consume of psychoactive substances, abuse, exploitation and negligent treatment.” (Focal Group, Colombia, Instituto Alamos)

“They come from urban-outskirts neighbourhoods; many of these homes have problems with basic sanitary conditions and access to services (mainly health and education). The level of education of the families is generally low, and the majority of them are dedicated to the informal economy or have temporary employments.” (Focal Group, Bolivia, ASPACHIDEM)

“Families live far away from the Foundation, in somewhat violent zones, even when some of them have their residences in safe blocks. The families have public services, health centers, and public transportation with

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limited schedules. These are families of low economic resources, with parents older than 35 years of age, and with low levels of education. Parents, preoccupied by the situation of their sons and daughters, are searching for solutions. These persons are opened to new ideas and talk in a calmed way, about their experiences as parents of children with disabilities.” (Focal Group, Colombia, Fundación Integrar)

“This family lives in the Pujili canton located near Latacunga, where they have basic services. Their house is made out of cement, but they have unfinished roofs due to the lack of resources. The house has a bedroom, bathroom, dining room and kitchen. The parents and their son with a disability sleep in the bedroom, and their older daughter sleeps in the dining room. They have a television in the bedroom, as well as many medals that were proudly won by their son in the Special Olympic tournaments. The community is very supportive and they make up for necessities in a mutual way. The family lives mainly around their son’s necessities.” (Grupo Focal Ecuador)

“The participants were four parents of the rural area, and eight parents of the urban one. One Ladin Mother and 11 indigenous parents; only three of the participants know how to read and write, and none of the participants have done elementary school. All of them are from the Santiago Atitlan municipality and its communities. In two of these families, there are alcoholism and drug addiction problems; and most of the families eat two times a day. The average of the children of these families is six. There are some families with up to 10 children. Two families have two children with disabilities. Four couples assisted (mother and father). The parents are labourers, with a daily income of Q 20.00. The mothers who participated have domestic trades and very low incomes for washing clothes or for making some type of craft of that place.” (Focal Group, Guatemala)

“The Casitas Canton, jurisdiction of the Santo Tomas municipality, department of San Salvador, is located at 12 kilometres of San Salvador city, with approximately 3000 habitants. Electric service exists in the majority of the houses. Potable water service is not generalized. There is one school that takes care up until sixth grade, without health service. The economic activity of the majority of the habitants is the agriculture, and this presents a generalized poverty level. This community has organized a RBC service, promoted by the Hogar de Paralisis Cerebral Roberto Callejas Montalvo (Cerebral Palsy Home of Roberto Callejas Montalvo), a private institution supported by parents, which has detected around three hundred persons with disabilities in the canton surroundings. The families participating in the focal group are integrated low income and low schooling families with children with disabilities that are making enormous efforts to bring up their children.” (Focal Group, El Salvador)

The facilitators of the focus groups describe in the following way what the families told them about their situation.

- The main difficulties are discrimination and rejection of persons with disabilities.
- The need to better understanding their child’s disability to improve their care
- To overcome the cultural prejudice that a person with a disability is “not created right”
- Illiteracy, in some countries, is a significant barrier.
• Not having the support of the family, in some cases, of the husband.

• Lack of adequate diagnosis, at a young age, worsens the situation of their sons and daughters with disabilities.

• In some countries, there is a language barrier in understanding the information that is being provided.

• No adequate access to information on the disability, and on how to help their sons and daughters.

• There are families, in some groups, that have more than one young child with disability.

• In some countries, the majority of the families with children who are not in school yet due to age and who have a disability, report difficulties in attending their jobs, especially mothers, due to the fact that there are no day cares for their children with disabilities.

• Families with scarce resources identify the need for guidance and health services. The specialized medicines that are needed are difficult to access and strain family income.

• Housing is a situation that preoccupies them due to the physical and psychological implication that it brings to the members of the families.

• At the same time, due to the specific rehabilitation that each boy or girl needs, for the same reason, they are at risk when it comes to natural disasters or unfavourable events.

• Families identify their challenges from the perspective of their sons or daughters needs and not directly in relation to economic factors. It seems that this situation of not having resources is not the main difficulty, but it is more important to resolve the care and attention situation for their children and families.

• In searching for a solution to the rehabilitation, education, care and guidance in the everyday life, they encounter more obstacles with economic factors and accessibility issues, not only for their members with disabilities, but for the entire family in general.

What adjusting strategies have families adopted?

None of the families have sat idle without doing anything for their sons or daughters. They strive to overcome challenges, searching for solutions, opportunities, and information that will allow them to find a way to improve the quality of life for them and their families.

Various individuals from the focus groups expressed the following:

• Learn to accept the disability, which takes a certain time in life.

• Search for help. Even though in some cases, the education of the parents is low.

• Involving children in different activities teaches people to learn to respect them, and not to hide them.

• Take them to school, so that they can learn and get to know other boys and girls.

• Ask for information.

• Search for other parents with the same problems (helps to feel accompanied).
• Search for methods of economic support in order to get the everyday support and meet the needs of their children.
• Utilise the generosity of families and neighbours to make up for the housing and food.
• Practice the suggestions that are offered by specialists in order to help their children with disabilities.
• Help and guide other parents that have children with disabilities, and who are younger.
• Fill jobs in the informal economy that allow them to meet some basic needs.
• Join other groups to achieve changes in relation to the attention to persons with disabilities.

It was a gratifying experience for the families who participated to have their OWN VOICES heard. These perspectives force us to recognise the knowledge that families have about the conditions they face due to poverty and disability. Therefore, local, regional and international initiatives can benefit from this knowledge. These families told us:

• “It is necessary to prove that the term “poverty” hides the true dimension of the persons with disabilities and their families” 5
• Take into consideration that if poverty is complex in itself, it is even more complicated for the persons with disabilities and their families.
• Consider in the plans that fight against poverty, the participation of persons with disabilities and their families is very important; it must be insisted upon Governments.
• There must be a break through the invisibility of the poverty and disability issue.
• There should be an insistence on how the problem of the poverty and disability is a public ethical issue, a responsibility of the state, society and the private sector. 6
• Identify the difficulties of accessibility to jobs for persons with disabilities, in order to search for viable attention and training alternatives.
• Permanent training and sensitizing programs directed to fathers and mothers, teachers and the community in general, on the disability issue that imply attitude changes.
• Insist upon Governments in order to create support programs on specialized medicines and to improve the health care.
• Support to mothers with children with disabilities so that they can work and leave their children in dignified and human care. 7
• Create family and community support networks that facilitate inclusion.

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5 Focal groups, Poverty and disability, in the Americas, 2004
6 Idem
7 Idem
3. **Civil Society Perspectives**

In order to understand the political and social context for the experiences and issues identified by people with disabilities and their families the study surveyed civil society organizations about the social and political processes in place to address issues related to poverty and disability in their country.

Many of the associations who responded and participated in the study are organizations of parents whose purpose is to promote better lives for their family member with a disability. These organizations are well situated to provide both basic information about the structures and institutional framework for poverty and disability but also to share an analysis of key issues that emerge when we take a closer look at the impact of poverty on people with disabilities and how disability is a contributing factor to poverty. From 13 country responses a number of common issues and challenges were identified. Countries were asked to describe the organization of the country; poverty reduction strategies; government and civil society organizations related to disability issues, the relationship between poverty and disability, legislation, statistics and initiatives around poverty and disability at a national, regional and local level (in the different sectors, including health, education, employment, etc.). (The questionnaires from which the following information was summarized is available on request from Inclusion International).

3.1 **National Contexts**

*(This section has been translated from Spanish)*

3.1.1 **Organization of the countries**

The Commonalities:

- All the countries are democratic republics organized on a federal basis with central government organization. Their current economies have structural adjustments and processes of economic openness.
- All of them report, that in the last few years, they have been in an economic crisis that has had a great incidence in the increase of poverty, concentration of wealth, increase in the gap between those who have more and the poor ones, increase in unemployment, and the social exclusion of vulnerable groups. Therefore it is difficult to achieve social development objectives outlined in various country documents. The majority of the countries have as a challenge the decentralization and to achieve citizen participation and community monitoring.
- Regions within the same country, have vastly different conditions.

“*The South and Southeast regions are the ones that are more developed, and the rest are way back, in terms of the human development and social indicators. This gap creates two ‘Brazilis’ – one that is very rich, and a very poor one.*” (From the report from Brazil)
• Emigration of the human capital as a result of the economic crisis is mentioned, and it is considered that this is a factor that generates poverty for the country.

The Differences:

• Even when the countries of the region share a high number of characteristics, they each have some distinct and distinguishable problems. In the Americas and the Caribbean five (5) countries have poverty reduction strategies (PRSPs) (Bolivia, Nicaragua, Honduras, Dominica and Guyana). Among problems listed by these countries as barriers to growth are: armed conflict, natural disasters and drug trafficking.

### 3.1.2 Poverty Reduction Initiatives

• The majority of the countries have poverty reduction plans and human development policies. The Human Development documents have a common approach to Social Risk Management (SRM) 8, Social Protection System (SPS) and contain a definition of ‘vulnerable’ populations and populations ‘of interest’.

• The groups responsible for the disability theme inside the World Bank, consider that the disabled population must be included in all the poverty reduction programs when it refers to vulnerable groups, marginalized population or those who are disadvantaged. But experience shows that when no explicit reference is made to people with disabilities and their needs, the strategies and programs that are relevant do not include this group of people.

• All the reports of the countries show how the category of vulnerable populations in these documents, does not include the disabled population within programs or initiatives focused on poverty reduction.

• In many of the reports, it is shown that even when the population with disabilities is explicitly identified as an important group within the documents of the reduction of poverty, when the country implements its strategies, they are directed to ‘groups of interest’ where the population with disabilities does not appear.

“Even when it is indubitable that the documents on poverty and those to confront the economic crisis of the country, they mention the disability as an element that generates poverty and they mention associated elements to poverty as variables that generate disability; showing, in this way, information that is irrefutable and known by all who relate poverty and disability. When the time comes to select the vulnerable groups, who will receive special attention (groups of interest)... the population with disabilities are not identified in any of the programs as a vulnerable group.

The groups selected in all of these documents as vulnerable and as beneficiaries of actions, do not necessarily represent the more numerous ones, thus the question is what criteria was used for this selection? (From the report from Colombia)

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• In some cases, unfavourable conditions are generated such as:

“The Human Development Bond has been the cause of many and reiterative claim. For example, the city of Manta, in May 2004, during a journey on training on rights and disability, where approximately 120 persons participated, at least one fourth of them denounced to have been omitted of the list of beneficiaries, being persons that live in high poverty levels. At the same time, this Bond is less for persons with disabilities because the family expenditure is not considered to be higher when the family has a member with a disability. It is simply assumed that this is a “personal problem”. (From the report of Ecuador.)

• The poverty reduction strategies in the different countries have some similarities: Nutritional complementation, aid linked to assistance and permanence in the schools and/or assistance in the activities of improvement of health, subsidies and programs to eradicate hunger, programs of action by youth and family, just to mention a few.

• The majority of these monetary contributions attempt to increase the provision of health and education services, and they are directed to the nutritional improvement or are financial strategies from micro-enterprises and expansion of social protection. Poverty is managed from a social policy for the social development, from the traditional parameters of the international agencies, where programs related to inclusion cannot be observed, and this is the aspect that stands out the most as the challenge of the families from the focal groups.

3.1.3 Disability Policy and Mechanisms for Consultation

• All of the countries have a National Council on Disability at the central government level, and in most cases, similar structures are repeated at a national and local level. The majority of the Councils do not have a budget, do not have regulations and their functioning depends heavily on the will of the government. In each of the countries that responded, the National Councils on Disability are reported to be non-functional structures at the moment, with little contribution to the improvement of the quality of life for persons with disabilities and their families.

• The majority of countries have a National Plan of Attention to Disability, which in the majority of cases outlines objectives and plans at a general level. Even when specific actions are identified in some of them, all of them lack the investment of funds required to be implemented. Therefore, these plans are far from being part of the strategies of social investment of governments.

• In the majority of the countries, important efforts have been made in order to advance the language and conceptualization of the disability towards the focus on the World Health Organization (WHO), in agreement with the guidelines of the social perspective, which proposed the new International classification of functioning, disability and health -ICF. There are a few countries, disability is still seen only as a health issue. The theme is far from being incorporated within the social development of the country.

• In all of the countries government plans identify similar priorities: prevention, opportunities, equity, and provision of services. They emphasize the need for public awareness and information about people with disabilities to promote inclusion.

9 OMS. Clasificación internacional del funcionamiento y la discapacidad - CIF. Ginebra, 2000
• Services in the majority of countries are financed by donations and international agencies (more frequently in the poorer countries), with little investments from governments. In many cases, the delivery of services is seen as charitable assistance.

• Community Based Rehabilitation strategies, focused on the poor population with disability and on social services in the most needed sectors, were identified in a number of countries.

3.1.4 Relationship between Poverty and Disability

• Country reports identify a cycle of poverty-disability-exclusion with innumerable factors that perpetuate this circle, making it hard to break.

• Re-thinking the issues of disability in relation to poverty, provided participants in the study with a fresh approach to their analysis of the exclusion faced by people with disabilities.

• Governments have identified a number of groups to whom they will target initiatives: less than one year of age, less than five years of age, pregnant women, nursing women, elderly, ethnic groups, boys in armed conflict, women, emigrants and displaced persons. Despite the fact people with disabilities are represented in each of these groups, there is no recognition of people with disabilities as a group or within other groups.

• This coincides with what was stated above about the need to specifying the population with disabilities so that, it can be included in programs of poverty eradication.

“Since persons with disabilities and their families are among the poorest of the poor, it is essential that the population is addressed and incorporated as a vulnerable group of interest, not only in the policies on disability, but in all the policies that are directed to reducing poverty and its impact on people and families, as a strategy to promote equity, participation and inclusion.” (From the Report of Colombia)

• In the majority of initiatives by international organizations identified in the reports, proposals around poverty and/or disability are not mentioned.

3.1.5 Statistics

• In the majority of the countries there are no reliable statistics in respect to the population with disabilities. Brazil, Chile and Nicaragua report the presentation of the greatest information around disability and poverty. For all of them, this is a priority issue and some of the countries are starting to generate information on this subject.

• Even when many of the countries report surveys on disability (ENDIS) from the organisms or national institutions of statistics and accomplish important efforts in this area, in the majority it is observed that the few facts that do exist are contradictory within the same country and are not reliable. The data cannot be compared between countries.

• It is argued that the lack of statistics may be a coincidence before the invisibility of the population, which is a frequent theme in the reports. Improvement of data collection is necessary in all of the countries and its urgency is identified in the proposed plans of attention to disability and in establishing a link between poverty and disability.
3.1.6 The Legislation and the Human Rights

- The legislative framework in force in the majority of the countries recognizes and guarantees the rights of the persons with disabilities. In the majority, they do this from the Constitution, from the ratification of International Instruments that benefit the population with disabilities – proposed by the United Nations, the Organization of American States (OAS), the International Labour Organization (ILO), for example, the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities – and in general, from the sectoral laws, basically on health, education and accessibility. Some have more recent laws and with better adjustments towards an updated conceptualization of disability and with focus on social inclusion. A few others require major transformations from their laws.
- All of the countries report the lack of regulations in the majority of these laws and their lack of compliance on the part of the governments.
- It could be said that there exists a generalized feeling that is summarized by the following phrase from one of the reports:
  
  “The fact of simply complying with the Politic Constitution of the Republic of Ecuador would be sufficient to effectively guarantee the exercise of the rights of the persons with disabilities” (From the Report of Ecuador)
  
- Throughout the work of the last few years, the discussion around the rights of persons with disabilities has dominated. A fight that has resulted in many improvements in legislation and awareness.
- Nowadays, violation of rights are more likely to include lack of access to services, lack of compliance with legislation, systematic social, economic and political exclusion and the rejection of the person with a disability, aggravated by poverty.
- Exclusion was identified most frequently as the greatest challenge facing people with disabilities and their families both in terms of disability and poverty as it contributes to inequity and isolation.

3.1.7 Education

- The general context of education varies widely among countries surveyed. In some countries education is a free service for all the population, while others state that only 60% or the population attends to school due to the lack of schools and teachers.
- Notwithstanding the situation of the education sector in the country, children with disabilities compared to non-disabled children are significantly disadvantaged.
- Between 4% and 35% of children attending school have a disability depending on the country. Consistently, it diminishes as it proceeds from elementary, to secondary and superior education. But the incidences of repetition, desertion (drop-outs), and extraction for the population with disabilities in comparison to those who do not have a disability, are known.
- Inclusive education has been the most important transformation at a global level in the last years. It is a recurrent theme that is intrinsically linked to human rights, in the Americas. Studies in this particular subject that were carried out by the organizations are included in many of the reports.
In the majority of the reports there is an openness towards inclusive education but special education is still managed as a separate service from the education ministries. This generates models of exclusive and segregated practices. The majority of countries report a section of the Ministry of Education dedicated to the attention of the population with disabilities or with exceptionalities.

One of the challenges identified in the country reports is the difficulty encountered in developing national inclusive practices. While many examples of good inclusive practice exist, these experiences have been difficult to generalize. Difficulties include organizational structure (education systems and schools) and the training of the teachers.

International commitments to Education for All, as well as investments in education reform are creating spaces to reflect upon different ways of providing education, particularly in developing and transition countries. There have been significant efforts in the region towards building an evidence and knowledge base around inclusive education, developing partnerships to promote and implement inclusive education, and strengthen the capacity of civil society organizations, governments and international organizations to work together to make inclusive education a reality.

Poor access to early childhood education (programmes for children under 5 years) is identified as an overarching issue for all children but particularly for children with disabilities and poor children because most of the existing programmes are privately run and inaccessible. Poor families who have a son/daughter with a disability do not have access to the same conditions as the families in equal circumstances but without sons/daughters who have a disability.

Very few employment training and labour market programmes exist for people with disabilities perhaps because of low expectations regarding labour market participation.

### 3.1.8 Health

- Health services vary depending on each country, but the need to increase coverage and quality was consistently identified as a priority.
- Affiliation to the systems, especially to the subsidies, does not guarantee the attention they require, due to ignorance, lack of information or because the costs continue to be too high.
- The distance that families have to travel in order to receive medical attention and rehabilitation is reported as a reason of why they can not access services.
- Despite inadequacies, in the majority of the countries surveyed the health sector is the one that offers the greatest attention to the population with disabilities.

### 3.1.9 Gender

- The information gathered from country reports in the area of gender is consistent with the World Bank reports on the MDG indicators showing that in the majority of the Latin American and Caribbean countries, there is no difference between boys and girls attendance in schools.
• Some of the reports show data in aspects that are related to caregivers. They identified that in the majority of the cases, the care giving responsibility of a person with a disability is assumed by mothers, grandmothers, daughters or sisters.

• Mothers of boys/girls with a disability have significant difficulties in finding and keeping paid work due to the fact that there is nobody to take care of their son/daughter, especially at an early age or when they are supposed to be at school.

• There was also data on homes that have mothers as heads of family, teenage mothers of boys/girls with a disability, and in relation to the increased mistreatment towards women. Some of the facts stated in the reports could represent the real problematic of the disability – gender inequality in the region.

3.1.10 Organization of the Civil Society

• In all countries surveyed, the majority of the NGOs provide services, this is largely due to the lack of health and education services and the investment in the decade of the nineties by agencies and international organizations that promoted this type of role.

• There are fewer organizations with grassroots membership that have assumed the role of advocacy, public policy and lobbying. It has to be recognized that these are few and that working at these levels requires training and supports.

• People with disabilities, their families and their organizations require training and capacity building in order to be effective representatives for their family members. In order to assure that the population with disabilities is included in all the government plans – including the ones on the eradication of poverty-in the regulation of laws and to guarantee their compliance in the daily practice, organizations of civil society must be equipped to mobilize the population and to contribute to public policy and its implementation.

4. Causes of Poverty

By ROBERTO MADRIZ, Inclusion Inter-Americana (Translated from Spanish)

It is not possible to successfully address poverty, if we do not confront its causes. Poverty, in itself, is an effect. It exists due to the concentration of a number of factors.

The information that was collected and synthesized in the previous chapters of this document reflects the reality that weighs down tens of millions of persons throughout the American Continent. In addition, it identifies a set of causes that generate this prevailing situation in the continental field when it comes to poverty and disability.
The main sources for the analysis that lead to the identification of the generating causes, which are presented in the next pages, was the information delivered by: Argentina, Bolivia, Brazil, Caribbean, Chile, Colombia, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Nicaragua and Peru, whose synthesis have given shape to this document.

At the same time, the conclusions emanated from other two important regional sources were taken into account:

- The Americas Social Forum, that took place in Quito, Ecuador, (July 25-30, 2004), which was attended by 10,000 persons from 45 countries. This event was held in preparation for the World Social Forum, which will come back to Brazil in January 2005.
- The World Education Forum, that took place in Porto Alegre, Brazil, in January, 2003, where more than 15 thousand people participated. The event identified historic and current factors that are combined in order to generate exclusion and inequality, and thus, more poverty.

The value of these events was the real representation of those who participated. They are the voices of the people and their social organizations. A voice that does not come from the interpretation of statistical tables developed from desks: it is the voice of those who suffer from poverty on a daily basis and have committed their lives to the battle for its eradication. Unfortunately, in both events, the voice of the persons with disabilities was practically absent, mostly, due to the minimal participation of national or regional organizations who concentrate on the social movements around disability. Drawing from the outcomes of these events will help to situate the poverty of people with disabilities in a broader framework for understanding poverty.

For the purpose of this report, the identified causes will be divided in three categories, with the understanding that these three complement each other, and are tightly linked. The three categories are the following:

- **Structural causes**, referred to social, political, economic and dominant cultural structure that have developed throughout history. It includes the generating causes of poverty that are profoundly rooted in the behaviour of the Latin American and the Caribbean populations and States, whose tackling must, therefore, be conceived as a medium and long term process.
- **Current causes**, where situations, whose genesis and development are relatively recent, can be contemplated. In this category, social factors and phenomena that worsen the conditions of poverty are considered. Yet, through the implementation of adequate State policies, they can be addressed in the short and medium term.
- **External causes**, where the streams of thought and action are not born in the Latin American or Caribbean sphere, but influence the particular conditions of each of the countries of the region in a determinate way, and are combined in order to increase the social gap and, consequently, the incidence of poverty.
Even though each country in the region presents its own unique issues, the common aspects, which act as a transversal axis are present throughout the Americas. These commonalities were taken as starting point in the analysis and identification of the generating causes of poverty.

4.1 Structural Causes

4.1.1 Exclusion

Societies in the Americas, present a highly exclusive composition, with prejudice in ample popular sectors. This implies that the great majority of the citizens find themselves with limited access to social goods and services. This situation, obviously, contributes to the perpetual increase of poverty and extreme poverty.

In the great majority of the Latin American and Caribbean countries, even at different degrees of incidence, the exclusion is basically expressed in four large areas:

- Economic exclusion
- Political exclusion
- Social exclusion
- Cultural exclusion

In Latin America and the Caribbean, the exclusion, apart from being expressed in the fields mentioned above, weighs with special emphasise on the shoulders of the weakest or most vulnerable people of the social structure. Among these, the following can be mentioned:

- **The peasant sector**, the poor rural person that is nowadays practically socially condemned to extinction, due to the fact that the dominant economic tendency considers it as an unviable economic subject. In the majority of the studied countries, the populations that inhabit the rural areas suffer material conditions of life that reflect even more poverty than the poor in the urban areas.

- **The workers of the informal sector**, this sector is growing rapidly as a product of the lacking and diminishing availability of regular labour, whose participants have their rights violated due to the fact that they are outside the shelter of the labour laws in force. The cross border plants, for example, violate in a daily and flagrant way, the labour legislation and the rights of millions of persons, mostly of working women. The owners of the plant will threaten to close and move elsewhere if there are forces to comply with labour laws. Due to this blackmail and other similar tactics that stem from growing unemployment and the urgent need to create labour positions, the labour rights are being ignored by national and international enterprises, and those responsible for watching over the labour laws in force turn a blind eye to the matter.
• The boys and girls, that already are classified as being on the streets and of the streets, technical categories that, in essence, talk about a reality that obliges them to stop being boys and girls. Adults of ten years of age, confronted since their early years by the harshness that mere survival imposes, denies them their childhood innocence by a society that excludes and denies them the right of being what they really are: children. On the other hand, the child-youth job continues to be one of the answers that the Latin American and Caribbean countries give to the situation of poverty, where they are immersed. The labour insertion of millions of boys and girls, mostly on the informal sector of the economy, has a direct effect on poverty.

• The youth, to which society does not offer any real proposal of ethical and satisfactory insertion to the labour force and community life. On the contrary, the majority of the youth in the Continent are witnesses of the consolidation of the social relationships model characterized by the predominance of the strongest one, and where the prevalence of a double morality that supports a democratic speech that notoriously contrasts with a customary experience that is marked by the stamps of inequity, exclusion and all their negative effects. The practice that is demonstrated from the State and form the big local and trans-national enterprises shows to the youth the value of the impunity, drives them to yearn for the easy money, to create a valid attitude towards corruption, and to underestimate the job as a generating source of income, among other similar doctrines.

• Women, who bear a double exclusion, due to the fact that they are marginalized for being poor, and also, for being women. The mere classification of women as the “weak gender” clearly shows a scornful vision from which the marginalization attitudes are emitted. From the “machismo” (male chauvinism), as a concept in many cultures in the Americas, arises a social practice that limits women in the full practice of their rights as citizens. Certainly, in the last decades, the feminist movement has accomplished important improvements in this field, but there is still much work to be done.

• Senior citizens, who are considered, from a social practice, as second class citizens. The predominant economic focus leads to societies to assume that the value that a person has, as the main purpose in life, is being productive. And therefore, the valuable contribution that can come from the accumulated experience of the older adults is undermined. For the dominant social model, the elderly are not a source of knowledge or advice, but rather, a ballast that has to be carried by those who are in the prime of their productive capacities.

• Indigenous people, whose culture is usually undermined by societies. This conception, in the end, permeates into society as a whole. The pluralism, even when it is an undeniable reality of many of the Latin American and the Caribbean countries, is not expressed in the main fields of the social relations. It is not recognized and it does not respect the right to sovereignty, to institutionalism and to the existence of systems of representation of the millenary cultures that have populated the Americas. The respect toward diversity has come to be, for some, more of a phrase used in order to adorn speeches that a real component of plans, programmes and policies that are formulated and implemented. On the contrary, for those who are more conscious, respect towards diversity has come to be, rather, a flag of struggle, a goal that has to be reached as soon as possible.

• Ethnic or cultural minorities, who find themselves in a similar situation as that of the
indigenous people, with the aggravating circumstance of being a minority, while the indigenous people in some countries is rather the majority. The afro-descendants, which add up to millions of inhabitants, have been witnesses to and victims of exclusive and marginalizing practices, which aggravate their material and spiritual conditions of life.

- **Persons with disabilities**, who constitute a usually invisible social sector, to the point that in the majority of national reports that were received in the framework of this investigation indicate that the population with disabilities is not referenced in the government plans under the strategies and programs to reduce poverty. Predominate visions of this marginalized population are marked by the seal of social work, pity and charity.

Obviously, those persons who are classified in many of the fields mentioned above suffer of many forms of exclusion. Haydé Beckles, self-advocate of the rights of persons with disabilities of Panama, summarized when she stated: “I am a woman, I am black, and I have a disability. How could I not be poor?”

The discriminatory practices that are present in the predominant social model in the Americas have their maximum expression in the manifestations of racism, xenophobia, and exclusion that come from these, influence and exacerbate the conditions of poverty.

### 4.1.2 Inequity

In the majority of the countries, the predominance of injustice, in its multiple forms, is evident:

- of rights and equality of opportunities, even when they are two basic conditions for the full practice of democracy, unfortunately, have not been developed, as they should. In the Americas, paraphrasing Orwell “some are more equal than others.”

- Liberty, one of the basic columns on which the Democratic platform is supported, has come to be in an exclusive patrimony of those who can pay for it. The rest of the citizens, even when they are surrounded by theoretic liberties, in their daily life they live surrounded by chains that oppress them and deny not only the access to development, but also, even, their human dignity. It has come to such a point that the liberty of the enterprise, of the legal person, imposes on the liberty of the human person.

- Fraternity, another of the columns where the concept of democracy is seated, succumbs before the prevalence of the laws of the free competition, which, in essence, signify the annulment of many of the weak in hands of a few strong ones. The law of the jungle, the law of the strongest one, is imposed, understanding by strength, not the force that emanates from the reason and the justice, but rather, generally the force that derives from the abuse of power.

- The administration of justice is not prompt or complied; its decisions are surrounded by impunity.

- One of the manifestations of inequity is expressed in the fact that the poverty, for millions of persons, is manifested in the way that the social and economic justice, far from advancing, it recedes. The existent plans and programmes that are intended to face poverty have turned out to be insufficient to compensate, if only, the massive effects of the exclusion and inequality.
4.1.3 Economic and Political Dependence

Sovereignty, comprehended as the right to free self-determination of the people, is difficult to be carried out in the region. In the majority of cases, the main decisions, mostly in the terms of economic policies and the exercise of the political power, (but not exclusively in these two fields) are taken outside the frontiers of many of the Latin American and Caribbean countries.

The economic and political dependence is translated, in the end, in absence of policies that are oriented towards the solutions of the main problems that afflict the poor population. The persons that are classified as poor suffer not only for the effects of the social and economic exclusion, as well as for their vulnerability, but also, for the effects of the lack of efficacy and efficiency of the institutional framework. Even when there are appropriate laws in place, the frequent scheme is that the problems are not resolved and the laws are not applied. The laws on the rights of the persons with disabilities constitute a clear example: they exist on paper, but not on the daily living. This component of the regional reality has clearly contributed to worsen the levels of poverty.

4.1.4 Unjust Fiscal Systems

In the great majority of the countries it is common that, at the moment of paying, the mechanisms to equilibrate the conditions of the poorest are not proposed or structured. On an almost daily basis, the governments put forward the lack of resources as an argument in order to justify the inattentiveness of many of their obligations. However, nothing or very little is done so that the coffers of the public treasury receive the amounts that should be paid by those who today, systematically or with impunity, know how to administer in order to protect their capitals so they are not obliged to pay what corresponds them.

Nations not only endure an unjust fiscal system, but also, collection mechanisms full of loopholes. The first demand, with urgency, is the revision and redefinition of the tax schemes so that they operate for the benefit of the majorities. The second one, in itself, is concatenated with questionable procedures and with bad habits of corruption.

4.2 Current Causes

4.2.1 Corruption

This component of the reality is combined with all the others already mentioned and with those that will be added in the following pages to worsen the condition of poverty. However, even when the corruption from the State is the most visible one, it is also manifested from other sectors. The corruption has found in the impunity, a protective shelter that guards it. There is a direct proportion in the relationship between the increasing corruption and the inefficiency of the judicial systems.
4.2.2 Worsening of Criminal Networks

The increase in the levels of violence has been constituted, throughout the American Continent, in one of the biggest problems that affect the citizenry. This rising violence is, without a doubt, a generating cause of increased poverty, due to the fact that it produces elevated levels of instability and uncertainty, which limit the possibilities for development.

Many countries in the Americas are being transformed, in an accelerated way, in places where there is a growing underestimation to the value of life itself. In Central America, for example, cities like Guatemala, San Salvador or San Pedro Sula, present indicators that show intolerable levels of violence10.

The violence is also increased from the strengthening of the diverse criminal networks, dedicated in a professional way to the traffic of drugs, robbery and decanting of vehicles, to the slave trade of women and children, kidnapping, and bank robbery, among other similar activities. Even in Ciudad Juárez, Mexico and in the Capital of Guatemala, recently, networks dedicated in a systematic way to the assassination of women have arisen. In numerous cases the relationship between the criminal networks, the police authorities and the military forces has been demonstrated.

The birth and accelerated development of juvenile defiant and violent gangs, solidly organized, who are owners of their own code of ethics and even armed with heavy weapons, is, at the same time, cause and effect of the exclusion and increased poverty. Some countries in this situation have opted for the road of repression as an answer and even have promulgated and put in effect “Anti-gang Laws”. However, they have not accomplished, in spite of this, to affect even in a minimal way, the levels of youth participation in gangs or the incidence of them in the violence indicators.

4.2.3 Predominance of the Neo-liberal Agenda

The international organisms have insisted in the idea that numerous nations, starting from the structural adjustment policies, have achieved important macroeconomic improvements. However, in some way the benefits of these improvements and of this stability have passed over the interests of the rights and necessities of the excluded sectors. The macroeconomic prosperity, in theory, should generate such abundance that it would finally reach the poor sectors. However, as it was stated by the former president of Costa Rica, Don Rodrigo Carazo, “the abundance goblet does not drip”.

On the other hand, the neo-liberal agenda places the States in a position that is more fragile each time and incapable of facing poverty and the causes that generate it. The policies of structural adjustment considerably limit the state possibilities of promoting plans, programmes and efficient and sustainable public policies that sponsor not the eradication anymore, but instead, at least, the reduction of poverty. The majority of the governmental efforts are focused around achieving the macroeconomic stability and

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10 In Honduras there are 70 murders for every 100,000 inhabitants; 90 in El Salvador and 113 in Guatemala. The World Health Organization considers “dangerous” a country, which has 10 murders for every 100,000 inhabitants per year.
administrating the external debt, instead of favouring the social investment and facing the internal social debt.

Among the main components of the neo-liberal policies that contribute to the widening of the social gap, the following must be emphasized:

- **Reduction of public expenditure in the areas of social services**: The governments are obliged to reduce their budget and participate in the areas that are vital for the population, such as education, health, housing, generation of employment, recreation, culture, and sports, for example. This budgetary reduction is translated, in practice, as an increasing deficit in the quality and quantity of the essential services.

- **Privatization of services**: Under the argument that the State is not a good administrator of the public services, these have been progressively privatizing. It even has been proceeded in this direction under false premises, such as the one that states that this process contributes to the community self-management and increases the levels of citizen participation. In the end, the process of privatization can place the services only to the order of those who can pay for them, and with this, it can clearly contribute to the aggravation of poverty.

- **Privileges to promote the external investment**: The States, in occasions, under the argument that they must open spaces for the creation of sources of employment, but in others, under the pressure of trans-national instances, benefit from foreign corporations and even local franchises, in prejudice of the rights of the workers, even when these rights are, in many cases, protected by legislations in force. This type of investment, otherwise, contributes to the fact that the wealth generated by the badly paid jobs from national labour ends up in foreign coffers, and with this, the country becomes undercapitalized in a progressive way.

- **Priority in the attention to the external debt**: The accelerated process of external indebtedness that the Latin American and Caribbean countries suffered, has incited this debt to become, not external, but rather eternal. The governments are forced to prioritize the debt service, frightened in front of their creditors’ power. This is translated, obviously, in inattentiveness to obligations that the State has for its own population and it has repercussions in the worsening of poverty.

### 4.2.4 Increase in vulnerability in the event of disasters

The progressive worsening of poverty implies, at the same time, an increase in the vulnerability of the impoverished social sectors. The deterioration in the conditions of housing, overcrowding, housing occupation on the non-urbanized lands, the malnutrition, and illiteracy, among other factors, are combined to position the vast sectors of the population in conditions of high risk. This leads to the fact that in the event of facing natural disasters, the devastating effects are even greater. The same happens when it comes to a disaster created by the hand of human beings, such as wars, destruction of the environment, the migration from the rural areas to the urban ones, and other similar phenomena. The increase in the vulnerability is, at the same time, cause and effect of increased poverty. This creates
a vicious circle that millions of citizens are subjugated to: due to the fact that it is poor, it is more vulnerable, and because it is more vulnerable, it becomes poorer.

4.2.5 **Poor spaces for real citizen participation**

In the majority of the countries, the spaces for real participation of the citizenry are limited or nonexistent. To the organizations of the popular sectors it is conceded the right to talk, but they are hardly listened. The quality of the participation is still a theme that has to be tackled and resolved. This component of reality is translated, in the end, in an increase of the social conflict and social mobilizations.

The social audit, as a mechanism that allows the population to supervise the execution of jobs that are carried out by the public institutions, is a field where the accumulated experience does not exist or is not sufficiently developed. The same can be said on respect to the political incidence that, as an instrument, should allow the popular sectors to have access to the field where the public policies linked to their necessities and interests are defined.

4.3 **External Causes**

Apart from the structural causes and the current causes that are the focus of the previous paragraph, a set of factors which are produced outside of the Latin American and Caribbean, contribute to the worsening of poverty. Among these, the following are emphasized:

4.3.1 **Unequal Relations of Exchange**

The seal of inequality marks the commercial exchange between the Latin American and Caribbean countries and more developed countries. The products, mostly agricultural and livestock products of the South, have a low price. At the same time, the industrial production of the North is priced at bigger costs each time. This fact, added to those already described, contributes to the increasing in levels of poverty and extreme poverty of the countries of the South.

4.3.2 **Dispossession of One's Own Resources**

The right to production and reproduction of generics and seeds is profoundly affected with the use of the legislation of international “patents”. Agriculturist and citizens are prohibited from using their own seeds and natural resources which can be found in their own territory and which they have used for centuries. In this way, the wealth of the countries ends up as property of other countries or of corporations, thus, impoverishing those who should be enjoying those riches.
4.3.3 **Policy on Continental Security**

World security imposes as a priority the use of the scarce economic resources in the plans related to this, so that the investments in social plans and in the development of human capital of the countries diminish considerably.

4.3.4 **Management of Natural Resources**

The use of its own natural resources as patrimony of the planet causes that the countries start to experience shortages of water, flora and fauna, due to controls or decisions from foreign countries.

4.3.5 **Foreign Plans and Programmes**

Countries are constantly subjugated to several impositions derived from plans formulated in a global way, but usually with little or poor participation of the national governments. It is about plans, programmes and policies that reflect and protect the interests of developed countries, while wounding the economies of the dependent countries.

This happens, for example, with the following initiatives:

- **Puebla-Panama Plan**: It is a plan that is already underway, conceived since Washington and promoted from Mexico, but it involves all the border of the Centro American isthmus, from Puebla to Panama. They are not formulated in response to the needs or basic problems of the population, but they respond to the necessities and interests of other sectors.

- **Free Trade Agreements**: These treaties, profusely promoted and underwritten throughout the last years, are immensely questioned due to the impact they have on the poor.

- **No commercialization of generic medications**: Populations, mainly, are nowadays forced to do without quality and low cost medications, as the generic ones. The majority of the States (both, the Legislative and the Executive Powers) have been obliged to approve laws that prohibit the commercialization of generic medications. With this measurement, it benefits, in an exclusive way, the big enterprises that produce medicines and it damages millions of inhabitants, for which the access to health turns out to be more unattainable each time. Also, in this case, the organizations of the popular sectors have applied pressure in order to preserve the right to health. Obviously, the lack of the medicines that is derived from this measurement contributes to the increasing in levels of poverty. The persons with disabilities and their families, in particular, are severely affected, due to the fact that in numerous cases, they need to acquire medications that now can be found in brand name ones, but that are more expensive.

- **General Laws of Concessions**: In numerous countries of the Continent, law proposals have been presented, that if approved, will authorize Governments to give in concession a long list of state goods and services. Among these, the following can be contemplated: education and health services, sources of potable water and aqueducts, post offices, telegraphs, telephonic services, ports, jails, airports, public transportation, broadcasting, etc.
The main argument that is employed revolves around the fact that the State does not have the capacity of providing quality services and, therefore, it must concede its administration to the private sectors. In addition, the private sector, in order to make these services efficient, will invest huge amounts of capital, with the fair expectation of recovering them and obtaining interests that must be derived from them. In other words, State goods and services would be rented, in order to profit from them.

This process leads to the privatization of essential services, as well as the private exploitation of vital resources such as water. Rights, such as health and education, which in most Constitutions are consigned as non-delegable obligations of the State, can turn into inaccessible ones for those who lack of solvency to pay for their costs. This fact, if it were to be materialized, will contribute in an evident way to the worsening of poverty.

The following chart represents the challenges that were identified in both the focus groups and in the country reports. It also outlines some of the recommendations made for dealing with the issue of poverty in the context of disability.
### SUMMARY OF ISSUES IDENTIFIED BY FAMILIES

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<th>CHALLENGES</th>
<th>RECOMMENDATIONS</th>
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| People with disabilities are not visible within country development strategies, including the poverty reduction strategies. | • To comply with the process of decentralization, local power has to be strengthened, which would mean fortifying participation and citizen control.  
• Citizen participation can be responsible for triggering a process of change within an inclusive system.  
• Intensify actions that influence public policies based on communities experiences.  
• Increase visibility of the issues of poverty for people with disabilities. |
| Community organizations of people with disabilities and their families, as well as Non Governmental Organizations, lack the ability to mobilize and transform public policies, including poverty reduction policies. They lack the capacity to influence the government decisions in the area of policy development and human rights. | • Strengthen collective movements. It is necessary to influence the following aspects:  
  — The formulation of public policies.  
  — Demand compliance under the current legal frame.  
  — Influence government authorities so that they encourage policies from a more inclusive perspective.  
• Trigger the social debate around poverty issues pertaining to people with disabilities.  
• Search for and promote direct participation of people with disabilities, their families and specialized civil organizations, in defining structured policies of poverty reduction.  
• Fortify disability organizations and increase their capacity to influence civil organizations.  
• Insist that the problem of poverty and disability is an issue that affects and must be addressed in both the private and public sector |
| People with disability are excluded from programs that are being developed in other social sectors.  
Governmental and international agency policies often result in exclusion and the limits access to social goods and services to minorities and segregated groups. | • Implement processes of Community Based Rehabilitation -CBR  
• Establish alliances with different social sectors aiming to eliminate the existent social barriers. |
| Overcoming exclusion, segregation and solitude is considered the prime challenge that families encounter.  
There is a lack of support from other family members as well as communities and society in general. | • Increase awareness and implementation of widespread community information programs.  
• Generate attitude change towards people with disabilities and their families.  
• Generate efficient connections between: International Organizations, NGO, GO, Universities, Parents association and people with disabilities.  
• Increase solidarity of efforts and knowledge towards promoting inclusion and rights for people with disabilities and their families. |
A forum titled “Poverty and Disability: Toward Inclusion” was held in Managua, Nicaragua, on 11, 12 and 13 August 2004. It was attended by: persons with disabilities, parents of persons with disabilities, professionals, government representatives, multilateral agencies, non-governmental organizations and persons who are active in the sector. Twenty-four countries from the Americas were represented. A participatory methodology was used, including reports from fourteen countries grouped into five sub-regions (Mexico, Central America, the Andes, the Southern Cone and the Caribbean). There were plenary sessions and group work, followed by presentations of the reflections and conclusions reached by the groups. The contents of the Forum focused on four themes: human rights, health, education and gender, with poverty and disability as cross-cutting issues.

The research carried out prior to the forum on poverty and disability in the region is an extremely important tool that identifies important commonalities among the countries of the region, while simultaneously uncovering differences, based on the reality in each country. The research aids in developing intervention programs. The studies provide insight into some consistent challenges in the region, such as the violation of the rights of persons with disabilities and their families and the prevailing attitudes marked by marginalisation, rejection and exclusion. It was found that people with
disabilities and their families are excluded not only from accessing social goods and services, but also from participation in their community.

The families of persons with disabilities have been kept submerged between feelings of shame and guilt, confining their disabled family members to anonymity and what many describe as invisibility. Proof of this is found in the scarce interest shown by governments; up until a few years ago there were no statistics regarding this population group, thus making the problem “invisible”. At present there are some statistics that while not entirely reliable, do provide basic information that now must be improved upon. Similarly, the persistent welfare-type approaches and attitudes towards persons with disabilities and their families perpetuate negative stigmas.

Earlier studies show that the needs and situations faced by families that have a member with a disability are similar to those expressed in the context of and in studies regarding poverty. Neither of these groups has access to education, in one case for lack of economic resources and in the other due to a disability.

Part of the success of the various initiatives both at government and at civil society levels can be attributed to the active participation by parents and persons with disabilities. In the search for ways in which to meet the needs of people with disabilities, it has been demonstrated that not only material goods are to be considered resources, but the entire system as a whole. The manner in which the system responds to the various requests being made can be one of the most important resources to break the cycle of poverty and disability. The reports presented at the forum, and indeed the proceedings in general pointed to the need for a strengthened base of family based organizations and strategies to use successful experiences to systematize inclusive practices.

This vision of sharing new and more innovative tools/resources has been a product of the creativity displayed by both parents and technicians. The innovation is an outcome of the lack of material resources with which persons with disabilities and their families tackle the day-to-day problems challenges.

### 1.1 Poverty and Disability: An Analysis

Although in the countries of the Americas there are limited statistics that specifically reflect the mutual relationship, prevalence and impact of poverty and disability, a detailed analysis of data provided by governments, international agencies and non-governmental organizations working in the field of disability on the continent, and an examination of the relation between disability and poverty, clearly point to the fact that these phenomena determine each other mutually. Put otherwise, disability predisposes poverty, and poverty includes factors that facilitate events leading to disabilities.

Families with a member who has a disability that live in conditions marked by limited resources, including the lack of basic goods and services crucial to subsistence, are exposed to consequences such as the following:
• Greater risk that a family member be born with or acquire a disability;
• Social or work-related disqualification due to prejudice;
• The traditional approach of viewing disability from a medical perspective only;
• A deficit of human and technological resources to treat disabilities; and
• Lack of effective spaces for persons with disabilities or their families to participate in the definition of public policy on poverty issues.

Above all is the most serious disadvantage: the existence of historical or structural reasons that over time have been the root cause for the persistence of these phenomena:

• structural poverty (extreme and relative)
• development model (centre – periphery)
• cultural attitudes (justification of disability as something normal)
• inclusion and recognition of rights is not deeply rooted in the culture

The available data from the various countries that was presented at the Forum contributed to a full understanding of the thesis regarding the self-perpetuating cycle of disability and poverty, which has for its foundation the structural causes identified regarding poverty. These in turn have a direct relation to immediate causes, which when added to a situation of disability, lead us to the direct relation between poverty and disability, and the situation lived by the affected families on a daily basis.

THE SELF-PERPETUATING CYCLE OF DISABILITY AND POVERTY

The effects of a life lived with a disability and in poverty are even greater when families live in rural areas, given that this is where the poverty and exclusion indicators are at their highest levels.
If we focus our analysis on the additional factors that increase the risk of poverty, many of them are associated with disability, as is reported in the Bolivia Country Report: “The neighbourhoods they come from are urban or in the urban periphery, and homes often have problems regarding basic sanitary conditions and access to health and education services. The schooling levels of these families tend to be low, and most work in the informal market or hold seasonal or temporary jobs.” (Bolivia Focus Group ASPADICHEM).

### 1.2 Poverty Measurement Methodology

At this juncture it becomes relevant to point out that the poverty measurement methodology used in some of the countries is the most often employed internationally, known as the “income method” or the “cost of basic needs” method.

According to this standard, an individual is considered poor if his/her level of income is beneath a minimum level that allows for satisfying basic needs. Someone is indigent if his/her food intake is insufficient. These minimum levels are known as the “poverty line” and the “indigence line”, respectively.

Although these poverty measurement methodologies have allowed some countries to build comparable indicators over time, which is an indispensable requirement to establish and evaluate their evolution, it must also be said that poverty is more than merely a lack of the material resources needed for survival. This quantitative poverty measurement approach infringes on “basic ethics” because it degrades the lives of thousands of persons who have a right to a decent existence in which they can build on themselves and fulfill their hopes and aspirations in their entire human dimension.

Poverty is limitation, the economic inability to “reproduce life”, the denial of educational opportunities that may culminate in a profession and the enjoyment of art, culture and leading an acceptable existence.

Today, with the availability of data that allows us to show that persons with disabilities and their families are amongst the poorest of the poor, it becomes fundamental that this sector of the population be taken into account and incorporated as a vulnerable group of interest. Advocacy must not merely concentrate on specific policies toward disabled persons, but be involved in all policies geared toward reducing poverty and its impact upon people and their families. Policies must promote equity, participation and inclusion.

In most cases, the difficulties faced by persons with disabilities and their families are not related to disability as such but rather with the discrimination which they are the object of, as well as the socio-economic and cultural barriers that limit their personal and social development, as well as the exercise of their full rights.
It is known and quite obvious that living conditions have a profound effect upon people with disabilities and their families. In countries such as Chile, between 60% and 70% of mental disability and other neurological disorders have their origin in what is known as “socio-cultural deprivation”. In other words, the quality of life has a direct influence upon the prevalence of these indicators, and therefore the impact of disability could be reduced by improving the quality of life among the population, with all the benefits that this implies for a nation's inhabitants and their country's development.

Analysis permits us to visualise the prevalence of a human rights and social reality approach to the definition of strategies for tackling poverty in most of the countries participating in the initiative. However, these approaches are not yet tangible for persons with disabilities and their families.

From a human perspective, it can be noted that, “these families have been forced to seek adjustment mechanisms in order to improve the quality of life of their sons and daughters with disabilities. Even when these mechanisms are not ideal, they have allowed families to mobilize and meet their basic needs, through mutual support and with the hope that these experiences will make it possible to seek out strategies that facilitate social inclusion.”

1.3 Working Group Discussions

1.3.1 Reflections on the Causes of Poverty

The working groups identified factors that increase poverty for people with disabilities, as follows:

- the state does not provide an adequate response to basic needs;
- corruption;
- inequity in the distribution of resources;
- scarce medical staff, teachers trained therapists;
- limited or non-existent proposals for education leading to employment and scarce job opportunities; and
- the educational system does not allow for all those enrolling to attend, and the quality of education is far from what is required by inclusive education.

1.3.2 Strategies Identified

The working groups examined these challenges and proposed some specific proposals such as:

- Prove and maintain the relation between poverty and disability.

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11 Las Voces de las Familias: la Dimensión Humana (Voices of the Families: the Human Dimension), Poverty and Disability Forum, August 2004, Nicaragua.
• Awareness-raising that generates empathy towards persons with disabilities, their rights and present conditions.
• Create community support networks at local and multinational level in the Americas.
• Have the Forum issue a declaration and make recommendations.

It should be pointed out that in the entire process the most valuable thing was to be able to hear people’s VOICES. The great challenge is to understand what lies behind these declarations and try to put forth strategies that are responsive to what people feel and express. Among these are statements such as:

“Persons with disabilities and their families are not a priority on the agenda of those in power.”

“They do not see us because we are poor.”

Despite the signing of Statements, Declarations, Agreements, Conventions and so forth, which for the most part are not implemented, we see that the causes of poverty are related to the inequality in the distribution of resources and an undervaluing of people with disabilities, which in turn leads to attitudes that foster exclusion.

Macroeconomic indicators in some countries in Latin America may show positive results, but the benefits that the populations at large may derive from economic growth depend upon the progress made in diminishing inequities.

The legal framework of almost all countries in the region is very broad, ranging from constitutional precepts, Equal Opportunity Laws and the creation of National Councils, to coercive measures as set forth in laws or regulations such as Brazilian Federal Law No. 7853 (1989) which establishes that discrimination is a crime, with the Public Ministry in the role of guarantor of compliance with the Constitution.12

However, the various civil society organizations pointed out that government authorities do not ensure that these laws are enforced, and in any case, the population living in a situation of poverty and marginalization is not cognizant of these rights, which is the reason for which they do not demand them.

It must be recognized that in most cases the legislation has not been an outgrowth of government initiatives, and thus the existence of this considerable amount of laws and regulations are the output of social pressure exercised by the different movements of and for persons with disabilities, as well as the advocacy work done by international organizations in favour of the rights of persons with disabilities.

It is contradictory that although legal frameworks exist, and are in some cases technically very well prepared, the national budgets do not reflect them or the policies derived from said framework or the laws.

12 From the CORDE Presentation, by Isabel Mainor from Brazil.
The statement “They do not see us because we are poor” makes it clear that one of the main challenges to be overcome is the invisibilisation of the reality faced and lived in by a person with a disability.

There continues to be a lack of coherence and synergy in regards government policies toward persons with disabilities. It is not sufficient that the issue merely be present. Rather, budget line items must reflect the plans and programmes. The population with disabilities must be explicitly mentioned, rather then forming part and parcel of a vast sector of the population known as “vulnerable” or “marginalized”. Another important aspect worth mentioning is that it is necessary that public policy transcend the period in government of a particular party. In our countries there is a tendency that after an election the advent of a new government means a tabula rasa from which everything that went before, including the good, is erased.

It is only in the last few years that persons with disabilities have been included in censuses questions. Specific surveys on the sector are an even more recent phenomenon. This is the strongest possible proof that the situation of persons with disabilities has historically not been visible. Although these surveys now exist in most countries, organizations of and for persons with disabilities have questioned the ways in which these measurements have been made. For instance, they do not include an important segment of this population, made up of those who are under six years of age. This causes a bias in the sample and makes it impossible to understand the situation of this age group. The consequence is that the surveys are little more than a set of statistics lacking in credibility. What is clear, however, is that in any population group selected, that which is received by persons with disabilities is always less than what their peers without disabilities receive. Also an important and very much questioned aspect is access to timely and relevant information.

Another difficulty is that organizations of and for persons with a disability are not involved in the processes prior to actually taking the surveys or censuses into the field. It is in this stage that important decisions are taken as regards the selection methodology, size and characteristics of the sample, issues to be included and so on. Thus the suggestions and contributions that might be made by organizations of and for persons with disabilities are not taken into account. In some cases they have been asked to participate in the presentation of survey or census results to the media, but as persons with disabilities they have expressed their disapproval through the slogan: “Nothing about us, without us”.

The availability of credible data will allow us to achieve a greater level of influence in those spheres where this is necessary. Without real and reliable statistical data, society at large will continue to minimize or ignore the reality in which persons with disabilities and their families live. In addition, we as societies will continue to miss out on the contributions that these persons are able to make in fields such as education, economy and politics.

1.3.3 Priorities

The national Poverty Reduction Strategies that have emerged as an outcome of the commitments taken
on by governments vis-à-vis the various multilateral organizations, and which exist in all of the countries in the region, have not seen the direct involvement of persons with disabilities. It is therefore fair to assume that these do not include specific strategies for reducing poverty among this segment of the population. There are, however, statements regarding integration, in which general commitments are made in terms of attention to vulnerable groups.

It is important to measure the impact of the different programmes financed by the multilateral organizations, for while it is important to have information regarding vulnerable sectors, it is necessary to know how to strengthen them. The impact of these plans and programmes should be therefore also measured for the purpose of establishing their cost-benefit ratio.

For organizations of and for persons with disabilities it is a priority that the public agenda should include the issue of poverty and disability. It is based on the knowledge acquired regarding this relation that concrete initiatives to tackle the problem of poverty among the population with disabilities must be taken. It is thus necessary to counteract the lack of information on the subject.

By doing so the reality that persons with disabilities and their families live in will be made more visible. It is a process that must start in our immediate setting, and it is necessary that members of organizations of and for persons with disabilities become multipliers in the determination of the relationship between poverty and disability.

Other priorities that were expressed are as follows:

- Awareness-raising among society in general;
- Access to quality public services;
- Greater participation by persons with disabilities;
- Strengthening of organizations of and for persons with disabilities from a rights perspective;
- Public policies that ensure the integral development of persons with disabilities;
- Make “Inclusion International” and “Inclusion InterAmericana” better known in the different countries; and
- Collect and apply lessons learned from positive experiences in the various countries

All of these priorities are equally relevant. It is the reality of each country or society that determines their order of importance.

1.4 Forum Conclusions

Despite the various plans and programmes being implemented by governments in the struggle to reduce poverty, among much of the population there persist high levels of social inequality, with people living in conditions of poverty, levels of schooling barely beyond basic education and significant problems as regards health, social exclusion and so on.
While it is true that these plans and programmes have had positive results in some countries, this has been mainly at a macroeconomic level. For the population at large these results have been imperceptible.

In order to be able to state that there is real progress in the well-being of the population, it is necessary that there be a decrease in the absolute number of poor persons and those whose basic needs are not satisfied. It must be stressed that the basic needs provided must be of good quality. In many countries little or no attention is paid to this important aspect, and it is considered good enough merely to increase coverage.

There must be follow-up of the impact being achieved by policy plans and programmes. This should take place during their implementation rather than when they have already concluded. Continual monitoring and evaluating of new programs offers an opportunity to make changes if the program is not achieving it's objectives, and makes it easier to establish their cost-effectiveness.

Organizations of and for persons with disabilities must take up the struggle in favour of poverty reduction, without losing sight of the human rights perspective. It is necessary to know and establish the relation between the organizations’ objectives and the MDGs, in order to capitalize on the opportunities that arise through funding and programming to achieve the MDGs.

The establishment of a relation between poverty and disability and the tuning of the interests of organizations of and for persons with disabilities with the MDGs will allow for opening up an area in which to exert influence. This carries an implicit need to strengthen the family based organizations.

Therefore the organizations should focus on the following aspects:

- Empowerment
- Knowledge
- Lobbying
- Information
- Advocacy
- Leadership
- Networks

It is necessary that the struggle against poverty not be limited to achieving positive results in terms of solely economic indicators, but rather that attitudes and values be generated that allow for reaching equality in the distribution of resources.

In order to achieve inclusion from a human and development perspective, it is necessary to work at both macro and micro levels, as follows:

*Macro Level*

This implies systematic lobbying and advocacy work at both national and international level. Inclusion Inter-Americana and Inclusion International play a very important role here, as a strong lobbying effort
will be necessary in those forums, seminars and so on attended by government authorities and donor organizations.

Leadership and knowledge are intimately related to the success of lobbying and advocacy efforts. It is important to point out that the forum titled “Poverty and Disability: Toward Inclusion” has ratified the human potential in the region. There is a great amount of accumulated experience as parents, experts etc., and this allows for exercising the leadership necessary in order to influence local and international policy.

In regards to knowledge, it is necessary to strengthen and follow up on the research initiative promoted by Inclusion International, which may be considered a baseline in the research process.

**Micro Level**

To achieve the empowerment of persons with disabilities it is necessary to work on the following:

- Strengthening of self-esteem, which will allow for their **interpersonal meeting** through dialogue and the facilitation of personal validation.
- **Self-help groups**, which provide opportunities for overcoming isolation.
- **Community organization** that creates conditions for facing common problems or situations and working in tandem to promote their interests.
- Being organized opens the possibility of greater **advocacy** for the purpose of achieving change in public policy.
- **Forge leaders** with the capacity to exert a positive influence on the system and people at large for the purpose of reaching the main objective, which is the integral development of persons with disabilities from a human rights perspective.
STRATEGIES IDENTIFIED BY FORUM PARTICIPANTS

Local/Community Level

• Organizations of and for persons with disabilities must take up the struggle against poverty, without losing the human rights perspective.
• Provide organizations of and for persons with disabilities and their families information so that they include MDGs in their activities in order to contribute locally.
• Strengthen management and advocacy capacity from the organizations to the different plans, programmes and projects being implemented by government agencies in their poverty reduction efforts.

Regional Strategies

• Design mechanisms that strengthen the information networks and generate knowledge regarding the issue of poverty and the link on disability.
• Identify inter-institutional and bilateral coordination spaces in which to participate and ensure a presence at government and international entities.
• Building and applying indicators to monitor activities geared toward meeting MDGs and their relation to poverty and disability.

Continental and Multilateral Strategies

• Establish a web site in order to suggest ways forward and monitor activities on the issue.
• Create alliances with research institutes and universities from a human rights standpoint and promote research that allows for diminishing the invisibility of the poverty and disability cycle.
• Disseminate information regarding Inclusion International and Inclusion Inter-American, its goals and activities to other already existing networks and identify strategies to achieve common goals.
• Establish a fiscal policy observatory in each country, in co-ordination with networks of NGOs, international cooperation agencies, UNDP, UNICEF, etc.
• Begin a social audit process on public policies adopted by governments of countries that are members of Inclusion Inter-Americana

“Today, because of data that allows us to demonstrate that persons with disabilities and their families are among the poorest of the poor, it is fundamental that the population be taken into account and incorporated as a vulnerable group that is of interest, not only within policies geared towards persons with disabilities, but also as part of policies intended to reduce poverty and its impact on these persons and their families, as a path that promotes equity, participation and inclusion.”

— By Inclusion International

13 Poverty and Disability Report, Ecuador, August of 2004.
2. HUMAN RIGHTS, POVERTY AND DISABILITY

By Inclusion International

Over the past ten to fifteen years the disability movement has adopted and promoted a human rights framework. In Latin America and the Caribbean the disability rights movement developed alongside the democratization processes in many countries. Families and disability organizations in the Americas have become frustrated by the limitations of the mechanisms that are available for implementing those human rights. Many of the human rights monitoring mechanisms while useful in raising awareness about human rights abuses, do little to put in place the institutional and cultural building blocks for societies that are inclusive of all groups. Poverty is an indicator of the failure to have those human rights achieved. Addressing the causes of poverty will help us to make those rights a reality.

The legislative framework in force in the majority of the countries of the Americas recognizes and guarantees the rights of the persons with disabilities. In most cases these rights are embedded in the Constitution through the ratification of International Instruments that benefit the population with disabilities – proposed by the United Nations, the Organization of American States (OAS), the International Labour Organization (ILO), for example, the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities – and in general, from the sectoral laws, basically on health, education and accessibility. Some have more recent laws and with better adjustments towards an updated conceptualization of disability and with focus on social inclusion. A recent study commissioned by the World Bank on Inclusive Education in Central America revealed that the majority of countries in that region have education legislation that requires the inclusion of children with disabilities in regular education systems. A few others require major reforms to their legislative frameworks.

Having established the language of human rights as the dominant approach to disability in the Americas and having institutionalized this approach through legislative mechanisms, disability advocates must now face the question, what is preventing the realization of these human rights?

For many individuals, communities and nations in the Americas the underlying barriers to participation and inclusion is poverty. The moment we turn our attention to poverty we must consider an array of issues; access to education, health care, housing, employment etc. In each of these areas the question to be addressed is why are people who have a disability excluded and how do we design systems which will include them?

Building on a human rights foundation in order to build an agenda to address poverty and disability has a number of implications in the Americas. It requires that we:

- a) acknowledge and provide information on the relationship between poverty and disability
- b) transform the way in which we measure disability and inclusion;
c) support disability organizations to take on the role of policy experts with governments and d) shift the way in which disability is addressed in development policy.

2.1 Measuring Disability

Policy makers and governments seek evidence that disability is relevant to development issues such as education, health care, poverty etc. Yet data on disability in LAC is poor. Little consistent data exists about the number of people with disabilities in each country or the impact of that disability on the household, income or participation rates. In part the lack of data is a reflection of the social and cultural invisibility of the population of people with disabilities as expressed in the research focus groups.

Defining and conceptualizing disabilities is a constant challenge in measuring and creating policy for disability issues. It is also however attributable to the fact that policy makers, governments and donor agencies have not framed the policy question to be addressed as an issue of poverty.

In order to collect information and data that is useful in the development of policy and program implementation, it must be clear what issue is being addressed.

If the disability agenda in the Americas was simply to prevent disability, then the data collection strategy would follow a health based model (the number of people with various forms of disability, health interventions etc.). If we want however to understand the barriers to participation that people with disabilities face in relation to various systems (education, labour market, political processes) we need to invoke different strategies for collecting information about the status of people with disabilities in relation to their environments and communities.

The challenges of data collection, conceptualizing and categorizing disability was articulated during a presentation at the forum in Managua by Daniel Mont, from the World Bank, who stated that;

“We need to establish the prevalence rate of disability in developing countries in order to provide an idea of the scope of the impact of disability on people's lives, but there are different prevalence rates for different conceptions of disability depending on the issue being addressed.”

2.2 Disability Movement

While the disability movement in Latin America might be characterized as a human rights movement, the organizational infrastructure that underlies this movement is largely a service delivery system. Disability organizations have, in response to the overwhelming needs in their countries, become the providers of basic services to people who have a disability. These services often include basic needs such as health care, education and employment, services that for the rest of the population are provided by governments.
Current support and investment in organizations related to disability are directed at delivering supports and services to people with a disability and their families because they are not being served by the general social, political, economic and health systems.

The challenge is to shift investments in civil society:

- From filling gaps in communities and societies to making systemic change
- From providing services to public engagement
- From out sourcing public and social services to making public systems accountable and sustainable.

In order to develop strategies to redress exclusion, disability organizations must have the capacity to engage in an array of processes:

- collect relevant information
- state, legislative and judicial reform;
- ongoing democratization of societies;
- development of human resources and economic development strategies; and
- planning initiatives to reduce poverty

The challenge for Inclusion Inter-Americana as one of the organizations enabling the disability movement in the Americas is threefold:

- To enable the voices of people who have a disability and their families in the region to be heard
- To build the capacity of member organizations to participate in policy dialogue
- To participate in the development of inclusive policies at the national, regional and international level

2.3 Disability and Development Policy

One of the key factors impacting on the status of people with disabilities in the Americas and poverty reduction is international development policy. Multilateral and bilateral development agencies have an enormous impact on the policies of governments in the region. The way in which these agencies conceptualize disability in the development context and the ways in which these policies and practices are implemented (or not implemented) have a definitive impact on the poverty of people with disabilities in the region.
Inclusion International recently conducted a limited scan of policies and research on disability and development at selected bilateral and multilateral institutions\(^\text{14}\) to gauge whether and how leading international institutions were incorporating disability into their international development cooperation. From this research resulted three main findings: 1) where there is a commitment to social inclusion in general, people with disabilities are often mentioned as part of the list of vulnerable groups without detailed actions for addressing the particular needs of people with disabilities and their families provided; 2) some international institutions have developed holistic policies on disability and inclusion demonstrating a real move towards recognizing disability and inclusion as a cross-cutting, human rights issue; and, 3) regardless of whether or not an institution has a specific policy on disability they have all conducted some form of research on disability and development of which the vast majority of this research discusses inclusion as a viable and rationale model.

Despite these encouraging findings at the policy level, the experience in the study of poverty and disability in the Americas demonstrates that there is very little institutional capacity to implement this approach. One area where this lack of capacity can be explicitly demonstrated is in the PRSP process of the World Bank.

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**PRSPS IN THE AMERICAS**

- In 1999, under the HIPC (Highly Indebted Poor Countries) Initiative, the IMF and the World Bank launched the Poverty Reduction Strategy Paper (PRSP) approach to poverty reduction in low-income countries. It aims to ensure that debt relief, and concessional funding through the IMF and the World Bank Group’s IDA address poverty reduction more effectively than in the past.\(^\text{15}\)
- At present, nearly 70 low-income countries are engaged in the formulation of national PRSPs that, once approved by the World Bank and IMF Boards, become the basis of concessional assistance from the two institutions.
- In low income, highly indebted countries people with disabilities are the poorest of the poor. In addition to the World Bank and the IMF, the analysis of completed PRSPs are increasingly influential on all development partners – private sector, bilateral agreements and multilateral institutions. The PRSP process therefore offers an opportunity to target people with disabilities to ensure that the development process is inclusive and improves their socio-economic status.
- In the Americas five countries — Guyana, Bolivia, Dominica, Honduras and Nicaragua — have

\(^{14}\) Agencies surveyed: Canadian International Development Agency (CIDA), United States Agency for International Development (USAID), Norwegian Agency for Development Cooperation (NORAD), STAKES' review Ministry of Foreign Affairs of Finland, Italian Ministry for Foreign Affairs (GDDC), Swedish International Development Co-operation Agency (SIDA), Department for International Development (DfID), European Commission (EC), World Bank (WB), International Labour Organization (ILO)

\(^{15}\) [http://www.inclusion-international.org/docs/pdfs/Disability%20&%20PRSPs.pdf](http://www.inclusion-international.org/docs/pdfs/Disability%20&%20PRSPs.pdf)
participated in the PRSP process. PRSPs in the Americas to date have been inconsistent in their inclusion of people with disabilities.

• In countries like Dominica and Bolivia people with disabilities may be identified as a particularly vulnerable groups, but then are left out of the entire policy implementation and formation.

• One country, namely Honduras, have integrated the inclusion of people with disabilities throughout their PRSP. This is demonstrated through consistent inclusion of persons with disabilities in their evaluations of progress.

• In many PRSPs, people with disabilities are consistently confined to mentions of “vulnerable groups”, “marginalized groups of society”, or “disadvantaged groups”. The ILO argues “Experience shows that whenever the specific exclusion mechanisms and specific needs of persons with disabilities are not explicitly identified, the related strategies and programs also miss their specific target.

• The PRSP sourcebook, a guide to PRSP development provided by the World Bank, makes clear the dueling perspectives on disability – it espouses a limited social protection approach that portrays people with disabilities as ‘welfare cases.’

  — According to the ILO “The Sourcebook has negatively influenced a number of (I)PRSPs, including those that have tried to include measures concerning disability and disabled persons.”

  — PRSP policies that attempt to address the concerns of people with disabilities focus on provision of services and not at all on creating inclusive structures.

  — Disability is explicitly included in examples discussing the need for social protection measures but rarely in discussions of empowerment and contribution.

• Evaluations of PRSPs in the Americas by the World Bank and IMF do not mention people with disabilities or offer any constructive critique of inappropriate policies regarding people with disabilities.
EXCERPTS FROM PSRPs IN THE AMERICAS

Guyana PRSP: The effective implementation of the growth strategy and equity enhancing measures described above should lead to increased income and reduced poverty. However, many of the poor are so far below the poverty line that improved prospects for employment or sizeable increases in their incomes will still leave them severely disadvantaged. Others, for reasons of age, disability, or illness, are unable to participate in the economy. P.32 The PRSP asserts that people with disabilities cannot participate in the economy, and implies that poverty reduction strategies which may work for the rest of society are not going to include people with disabilities.

Honduras PRSP: This PRSP does take some concrete steps to ensure the inclusion of people with disabilities throughout the PRSP and to engage people with disabilities in the consultation process. Initiatives include:

- Create the National Disability Council, with the participation of public and private institutions and associations of persons with disabilities, which will coordinate, direct and guide actions related to integral rehabilitation in Honduras.
- Create the Technical Unit for Integrated Rehabilitation to support for the National Disability Council in creating and implementing the National Policy, the National Plan and the agreements of the Council.
- A National Information System for persons with Disabilities should also be established.
- Create and implement at local level, integration and rehabilitation plans for persons with disabilities.
- Incorporate a module within the surveys of the National Statistics Institute, on various aspects of disability in order to identify, among other things, the geographic location and socioeconomic and demographic characteristics of the population with disabilities.

However, the PRSP reflects a social model of disability that is based on medical model assumptions. While people with disabilities will be targeted by new programmes that “incorporate a series of coordinated and viable actions that assure effective and comprehensive attention for extremely vulnerable or socially excluded people, in a framework of strong community participation”, assumptions remain that disability is something to be prevented and treated and rehabilitated. Further, programme details remain vague and it is unclear if the services will be provided in the community or in segregated institutions for people with disabilities.

Nicaragua PRSP: Particularly vulnerable, of course, are Nicaragua’s handicapped and disabled, since the prostrate economy can provide them little succor; they depend more on relatives and their community. But violence towards women and other family members often shreds that security as well… The magnitude of recent disasters and the extent of the poor’s vulnerability means only the government can develop the institutions and programs to provide them with stronger social protection mechanisms. P14
This PRSP accurately identifies people with disabilities as particularly vulnerable to poverty, although the assumption remains that their vulnerability is due to a lack of services and not the barriers which society presents. This PRSP assumes that people with disabilities are primarily service recipients in need of protection dependant on their families and on social programs. Further, people with disabilities are constructed as a drain on society and a problem to be solved through segregation and institutionalization.

According to some studies the disabled are more vulnerable than the rest of the population. They are more affected by health problems, but only 3 percent of them receive specialized health care. The disabled also have little access to specialized educational services. Exclusion for many disabled starts early in life at home, since many parents of disabled children prefer not to send them to school. P30

This analysis trivializes the exclusion of people with disabilities. It shifts blame to the family and does not explore the reality of society barriers to education. This analysis reinforces the belief that people with disabilities require separate specialized education and healthcare.

3. CONCLUSIONS AND NEXT STEPS

Through the voices of people who have a disability and their families, the study provides an analysis of the cyclical link between poverty and disability. The initiative in the Americas demonstrates that the way in which a person’s disability is experienced, both personally and within his/her community, is significantly impacted by conditions of poverty. Drawing from the knowledge of people with disabilities and their families about their own challenges as well as the experience of family organizations, this study points to significant policy issues in the area of poverty and disability. Those policy issues and recommendations for addressing them are in relation to each of the MDGs is contained in the chart at the beginning of this document.

The systemic link between poverty and disability can no longer be ignored. The findings of this report reflects the need for a shift in the focus of development assistance from the traditional means of addressing issues of disability as unique programming issues to begin to integrate disability issues into government, donor agency and NGO strategies across sectors at the national, regional and global level.
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MILLENNIUM DEVELOPMENT GOAL INDICATORS:

1. **Eradicate extreme poverty and hunger**
   - Population below $1 a day (%)
     | ... | 14.4 | 8.2 | 2.0 | 8.2 | ... | 31.1 |

2. **Achieve universal primary education**
   - Net primary enrollment ratio (% of relevant age group)
     | 94.4 | 94.2 | 96.5 | 86.7 | 99.5 | 88.9 |

3. **Promote gender equality**
   - Ratio of young literate females to males (% 15-24)
     | ... | 97.5 | 103.3 | 100.3 | 103.4 | 100.0 | 97.2 |

4. **Reduce child mortality**
   - Under 5 mortality rate (per 1,000)
     | 34.4 | 80.0 | 39.0 | 12.0 | 24.0 | 32.0 | 40.0 |

5. **Improve Maternal Health**
   - Maternal mortality ratio (per 100,000 live births)
     | ... | 420.0 | 260.0 | 31.0 | 130.0 | 130.0 | 150.0 |

6. **Combat HIV/AIDS, malaria and other diseases**
   - Prevalence of HIV, female (% ages 15-24)
     | 0.5 | 0.1 | 0.5 | 0.1 | 0.2 | 0.2 | 0.4 |

7. **Ensure Environmental sustainability**
   - Access to an improved water source (% of population)
     | ... | 83.0 | 87.0 | 93.0 | 91.0 | 85.0 | 77.0 |

8. **Develop a global partnership for development**
   - Youth unemployment rate (% of total force 15-24)
     | ... | 8.5 | 17.9 | 18.8 | 36.3 | 14.8 | 10.5 |
## Millennium Development Goal Indicators (World Bank)

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Guatemala</th>
<th>Honduras</th>
<th>México</th>
<th>Nicaragua</th>
<th>Perú</th>
<th>Venezuela</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population (in million)</td>
<td>11.7</td>
<td>6.6</td>
<td>99.4</td>
<td>5.2</td>
<td>26.3</td>
<td>24.6</td>
</tr>
<tr>
<td>Gross national income ($billion)</td>
<td>19.8</td>
<td>6.0</td>
<td>551.8</td>
<td>3.1</td>
<td>51.9</td>
<td>117.7</td>
</tr>
<tr>
<td>GNI per capita ($)</td>
<td>1700.0</td>
<td>910.0</td>
<td>5550.0</td>
<td>600.0</td>
<td>1970.0</td>
<td>4780.0</td>
</tr>
<tr>
<td>Total fertility rate (births per woman)</td>
<td>4.6</td>
<td>4.3</td>
<td>2.5</td>
<td>3.6</td>
<td>2.8</td>
<td>2.8</td>
</tr>
<tr>
<td>Life expectancy at birth (years)</td>
<td>65.0</td>
<td>66.0</td>
<td>73.1</td>
<td>68.5</td>
<td>69.3</td>
<td>73.3</td>
</tr>
<tr>
<td>Aid (% of GNI)</td>
<td>1.1</td>
<td>10.9</td>
<td>0.0</td>
<td>25.1</td>
<td>0.9</td>
<td>0.0</td>
</tr>
<tr>
<td>External debt (% of GNI)</td>
<td>21.7</td>
<td>80.8</td>
<td>23.9</td>
<td>173.1</td>
<td>52.6</td>
<td>28.0</td>
</tr>
</tbody>
</table>

### Millennium Development Goal Indicators:

1. Eradicate extreme poverty and hunger
   - Population below $1 a day (%)
     - Guatemala: 16.0
     - Honduras: ...
     - México: 9.9
     - Nicaragua: 45.1
     - Perú: 18.1
     - Venezuela: ...

2. Achieve universal primary education
   - Net primary enrollment ratio (% of relevant age group)
     - Guatemala: 85.0
     - Honduras: 87.4
     - México: 99.4
     - Nicaragua: 81.9
     - Perú: 99.9
     - Venezuela: 92.4

3. Promote gender equality
   - Ratio of young literate females to males (%15-24)
     - Guatemala: 92.5
     - Honduras: 104.6
     - México: 101.3
     - Nicaragua: 105.3
     - Perú: 97.1
     - Venezuela: 101.4

4. Reduce child mortality
   - Under 5 mortality rate (per 1,000)
     - Guatemala: 59.0
     - Honduras: 40.0
     - México: 30.0
     - Nicaragua: 45.0
     - Perú: 42.0
     - Venezuela: 23.0

5. Improve Maternal Health
   - Maternal mortality ratio (per 100,000 live births)
     - Guatemala: 240.0
     - Honduras: 110.0
     - México: 83.0
     - Nicaragua: 230.0
     - Perú: 410.0
     - Venezuela: 96.0

6. Combat HIV/AIDS, malaria and other diseases
   - Prevalence of HIV, female (% ages 15-24)
     - Guatemala: 0.8
     - Honduras: 1.5
     - México: 0.1
     - Nicaragua: 0.1
     - Perú: 0.2
     - Venezuela: 0.1

7. Ensure Environmental sustainability
   - Access to an improved water source (% of population)
     - Guatemala: 92.0
     - Honduras: 88.0
     - México: 88.0
     - Nicaragua: 77.0
     - Perú: 80.0
     - Venezuela: 83.0

8. Develop a global partnership for development
   - Youth unemployment rate (% of total force 15-24)
     - Guatemala: ...
     - Honduras: 7.2
     - México: 4.1
     - Nicaragua: 20.0
     - Perú: 13.2
     - Venezuela: 22.6

Data source: World Development Indicators database, April 2004, www.developmentgoals.org
ANNEX II

THE STUDY DESIGN

The findings contained in this research report are the results of a participatory research process conducted by Inclusion Inter-Americana with a team of consultants with expertise in disability and inclusion.

The research team designed a process to engage people with disabilities, families, civil society organizations and governments in the collection of three types of information:

- Data and existing research related to poverty and disability;
- Stories and experiences of individuals and families about the relationship between poverty and disability; and
- The policy context (legislation, programmes relevant to poverty and/or disability).

Using different tools to collect these different forms of information, the team organized its research into five regions of the Americas; North America (including Mexico); Central America, the Caribbean, the Andean region and the Southern Cone.

The participating countries included:

- Argentina
- Bolivia
- Brazil
- Caribbean
- Chile
- Colombia
- Ecuador
- Guatemala
- Honduras
- Mexico
- Nicaragua
- Peru
- El Salvador

The research in each region included a case study country in which more focused and detailed research was conducted and a summary of findings from the region as a whole. This research report draws together an analysis of the findings from across the Americas and the regional reports developed are available as annexes to this document.

The country reports collected provide quality and relevant information around the subject of the relationship between poverty and disability. In the majority of them, there is a greater knowledge and strength in the subject of disability, than that related to poverty. For this reason external expertise in the area of poverty was sought in many of the countries, who supported this second subject with their knowledge.
The initiative in general:

- Proposed a framework for the presentation of the information within a structured questionnaire.
- Mobilized an important number of persons and/or organizations in different countries.
- Involved other persons as statisticians and investigators of the disability and poverty theme.
- Generated 13 reports that can be used in the respective countries as a valuable source of information and mobilization of change.
- Generated a heterogeneous and complementary information in many cases from 13 countries of the region.
- It succeeded in obtaining reports with an analysis, on part of the authors, on the described situation supported on the knowledge that each of them has on the reality of their country. This facilitates, in an immense way, the type of global reports that are needed to be produced.
- The voice of the families and their relation with the poverty theme was allowed to get known through the focal groups.
- The job on Networks in the Americas was allowed, as Inclusion Inter Americana proposed it.
- Alliances with other organizations that are not part of IIA were included.
- The discussions in relation with poverty and disability in the region will be mobilized.
- It contributes with valuable information to be reviewed and discussed in the First Inter-American Forum on Poverty and Disability.
- It allowed collecting comprehensive and valuable information surrounding the aspects that are relevant to the initiative, that are shared by the region and distinguishing of the countries.
- It generated information that allows to obtain from the region, a global vision around the relationship between poverty and disability.
- It showed the possibilities of ‘linking local knowledge to global changes’.

There are people with disabilities living in every community in every part of the Americas. Often we don’t see them or hear about them because they are excluded from participating in schools, recreational activities and employment. Their families are also marginalized and excluded socially and economically.
Inclusion International and Inclusion Inter-Americana held a photo contest that encouraged people with disabilities, particularly people with intellectual disabilities, as well as their family members to photograph aspects of their lives; telling the world their story of what it means to have a disability in their country. This is the winning photo from Colombia.