INTO THE NEW MILLENNIUM:



INCLUSION INTERNATIONAL'S MILLENNIUM DEVELOPMENT GOALS

Inclusion International



CONTENT

Back	kground	
1.1	Introduction and Overview	3
1.2	Situating Inclusion International's Millennium Development Goals in the UN MDGs	4
Revi	iew of II MDGs	
2.1	Eradicating Extreme Poverty of People with Disabilities and their Families	5
2.2	Achieving Universal Primary Education for ALL Students	6
2.3	Promoting Gender Equality for Women with Disabilities	7
2.4	Reducing Child Mortality Rate Among Children with Disabilities	7
2.5	Achieving the Rights of Children with Disabilities and Families	8
2.6	Combating HIV/AIDS Among People with Disabilities	8
2.7	Ensuring Environmental Sustainability for People with Disabilities	8
2.8	Developing a Global Partnership for Development and Inclusion	9
Exis	ting Commitments to Inclusion & Human Rights	
3.1	Existing Commitments to Inclusive Education	10
3.2	Existing Commitments to the Human Rights of Children with Disabilities	10
3.3	Existing Commitments to the Human Rights of People with Disabilities	10
Con	clusion & Policy Recommendations	
4.1	Conclusion	11
4.2	Promoting Policy Dialogue on Poverty & Disability	11
4.3	Promoting Policy Dialogue on Education & Disability	11
4.4	Promoting Policy Dialogue on Gender & Disability	12
4.5	Promoting Policy Dialogue on Pre- and Post-Natal Care	12
4.6	Promoting Policy Dialogue on Rights of Children with Disabilities and their Families	12
4.7	Promoting Policy Dialogue on HIV/AIDS & Disability	13
4.8	Promoting Policy Dialogue on Human Rights & Disability	13



BACKGROUND

1.1 **Introduction and Overview**

Inclusion International (II) is making a difference in the world. By linking the voices of local partners to international initiatives and processes, Inclusion International is stepping closer to achieving its vision of full inclusion for people with intellectual disabilities and their families into all aspects of community life.

Building on a strong vision of human rights and inclusion, Inclusion International is now developing strategies to strengthen the capacity of governments, communities, civil society groups and multilateral institutions to develop policies and practices that are inclusive of people who have intellectual disabilities.

The UN Millennium Development Goals (UN MDGs) offers II the opportunity to fuse efforts from over 40 years of advocacy and action with international initiatives to achieve a unified vision of peace, participation and prosperity. Inclusion International is committed to contributing to the achievement of the UN MDGs by identifying common objectives that will enable sustainable and comprehensive development, directed at realizing the human rights of all citizens around the world.

Inclusion International's Millennium Development Goals mirror those of the UN to link efforts and achieve results for people with intellectual disabilities and their families. The UN MDGs are a set of eight time-bound and measurable goals for combating poverty, hunger, disease, environmental degradation, illiteracy, and discrimination, agreed upon by world leaders at the United Nations Millennium Summit (September 2000). II's MDGs provide a sound agenda for inclusive policy and programming in education, maternal and child health, poverty reduction, human rights, gender equality, HIV/AIDS and global partnership substantiated by clear targets that we are committed to working towards by the year 2015.

This paper provides an overview of Inclusion International's priorities in the areas of education, poverty reduction, children's rights, maternal and infant health care, ethical medical research and human rights. It provides both a realistic snapshot of the current situation facing people with disabilities and their families while outlining tangible policy recommendations to further international dialogue and action in inclusive planning, programming and funding.

Inclusion International (II) is a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide. II represents over 200 member federations in 115 countries throughout five regions: Middle East and North Africa, Europe, Africa and the Indian Ocean, the Americas, and Asia Pacific. Inclusion International has consultative status with agencies of the United Nations.



Situating Inclusion International's Millennium Development Goals in the UN 1.2 **MDGs**

UN Millennium Development Goals	II Millennium Development Goals	
Eradicate Extreme Poverty and Hunger: By 2015, halve the proportion of people living on less than a dollar a day and those who suffer from hunger	Eradicate Extreme Poverty For People with Disabilities and their Families: By 2015, people with intellectual disabilities and their families will live free of poverty and discrimination	
Achieve Universal Primary Education: By 2015, ensure that all boys & girls complete primary school.	Achieve Inclusive Education: By 2015, all children with intellectual disabilities will receive good quality, inclusive education with appropriate supports to ensure that each child reaches their highest potential	
Promote Gender Equality and Empower Women: By 2005 and 2015, eliminate gender disparities in primary and secondary education preferably by 2005 and at all levels by 2015.	Promote Gender Equality for Women with Disabilities: By 2015, social, economic and political discrimination against women and girls who have a disability and their mothers will be eradicated	
Reduce Child Mortality: By 2015, reduce by two thirds the mortality rate among children under five.	Reduce the Mortality of Children with Disabilities: By 2015, the mortality rate of children who are born with a disability or become disabled in the early years will be reduced by two thirds	
Improve Maternal Health: By 2015, reduce by three quarters the ratio of women dying in childbirth.	Achieve the Rights of Children and Families: By 2015, the rights of children with disabilities, as outline in the UN Convention on the Rights of the Child, will be respected; mothers will receive adequate pre- and post-natal health care to ensure the well being and healthy development of all children; families will get the help they need for the care and support of their member with a disability	
Combat HIV/AIDS, Malaria, and Other Diseases: By 2015, halt and begin to reverse the spread of HIV/AIDS and the incidence of malaria and other major diseases.	Combat HIV/AIDS: By 2015, the spread of HIV/AIDS in the community of people who have a disability will begin to be reversed and children with disabilities who have been orphaned will be supported and cared for in the community	
Ensure Environmental Sustainability: By 2020, achieve significant improvement in the lives of at least 100 million slum dwellers	Ensure Environmental Sustainability: By 2020, achieve significant improvement in the lives of people who have an intellectual disability and their families who live in extreme poverty	
Develop a Global Partnership for Development: Develop further an open trading and financial system that includes a commitment to good governance, development and poverty reduction - nationally and internationally	Develop a Global Partnership for Development: By 2015, global efforts to promote good governance and global partnerships will contribute to the human rights of people with intellectual disabilities, including citizenship and economic rights	



REVIEW OF II MDGS

2.1 **Eradicating Extreme Poverty of People with Disabilities and their Families**

By 2015, people with intellectual disabilities will live free of poverty and discrimination

Inclusion International advances the position that issues affecting people with disabilities must be included in all efforts to halve extreme poverty by 2015 (Goal 1, UN MDGs).

The World Bank estimates that there are approximately 1.3 billion people living below the poverty line worldwide of which people with disabilities make up around 20% of the 'poorest of the poor'. This translates into an estimated 260 million people with disabilities living in absolute poverty - not taking into account the poverty of their families. To put this another way, an estimated *one in five* people living on less than \$1 a day has a disability. This means that in order to reach the poorest of the poor and most isolated citizens, poverty reduction efforts need to target issues affecting people with disabilities and develop policies and programmes aimed at reducing their poverty.

Beyond the direct correlation between disability and poverty is the impact that poverty has on the human rights of people who have a disability. Poverty is fundamentally an issue of exclusion: the exclusion of some countries from the benefits of economic growth and the exclusion of some groups of people from generating and benefiting from social and economic wealth.

While significant poverty reduction strategies are being developed by governments, multi-lateral agencies and international financial institutions, issues of equity, participation and inclusion are left to human rights and legal judicial mechanisms for attention. The result is a disconnect between human rights systems and the systems that generate and control wealth. Current initiatives to combat poverty through international financial institutions and governments are not effectively, if at all, evaluating the exclusion of people who have a disability from economic and social participation in the construction of policies.

There are three key factors that have been widely recognized for leading to the further disadvantage of people with disabilities, their families and their carers. These include: (1) any additional costs associated with the disability; (2) loss of income to provide adequate and appropriate care giving; (3) exclusion from social services and community activities for people with disabilities and their families due to negative social perception of disability, inadequate infrastructure for physical access, lack of awareness of how to effectively design programmes that are both inclusive and welcoming, poor social networks for families, etc. Poverty reduction efforts must plan around these realities.

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2.2 **Achieving Universal Primary Education for ALL Students**

By 2015, all children with intellectual disabilities will receive good quality, inclusive education with appropriate supports to ensure that each child reaches their highest potential

Inclusion International strongly supports the promotion of universal primary education as outlined in the Millennium Development Goals: "Ensure that, by 2015, children everywhere, boys and girls alike, will be able to complete a full course of primary schooling"

According to UNICEF, less than 3% of children with disabilities attend any form of formal education, with the situation even more precarious for girls with disabilities. Establishing additional segregated schools is not feasible for most countries. Rather, money is better spent strengthening the capacity of community schools to handle children with diverse needs.

Segregated schooling is also undesirable from an educational standpoint. There is growing evidence that children with disabilities learn better when they are allowed to go to a public school within their neighbourhood. Often, it is the only realistic opportunity they will have to receive an education.

"Society needs to change and adapt to us. It needs to rid itself of its prejudice and create laws that are more fair"

> Pablo Pineda, Graduated from an inclusive university in Málaga, Spain

Education systems that exist for all children can be created with adequate funding targeted at community schools. Segregation and exclusion has failed. Inclusion and the good educational practice that comes with it offer hope to a region that needs to ensure educational equity and participation by all.

Commitments to adequate basic education for all children requires that we re-examine who accesses education and that we understand the conditions that create exclusion. In education the potential for progress depends on the development of policy, curriculum and practice that promotes and supports inclusion.



Kids Having Fun in School, Mali



2.3 **Promoting Gender Equality for Women with Disabilities and Mothers**

By 2015, social, economic and political discrimination against women and girls who have a disability and their mothers will be eradicated

Gender and disability have a twofold focus for attention and concern. The first is that girls and women who have a disability are doubly disadvantaged in accessing education, health care and employment due to discrimination against both their gender and their disability. The second is less obvious but almost equally isolating. Mothers who have a child with a disability are also doubly disadvantaged because they generally will bear the great majority of care-giving responsibilities, thus are not able to engage in other activities including employment and cultural activities, as well they are discriminated against because they bore a child with a disability – often devaluing and isolating mothers even more.

Addressing the discrimination faced by women requires a cross cutting examination of the roles women play in their communities and strategies to ensure that they are supported to participate in economic, social and political systems. For women who have a disability this will require both disability related supports and efforts to address general discrimination issues.

2.4 **Reducing Child Mortality Rate Among Children with Disabilities**

By 2015, the mortality rate of children who are born with a disability or become disabled in the early years will be reduced by two thirds

The Millennium Development Goals state two targets to address the health and well-being of mothers and their infants. These are: "Reduce by two thirds the mortality rate among children under five" and, "Reduce by three quarters the maternal mortality ratio"

Mortality for children with disabilities is estimated to be as high as 80% in countries where under-five mortality as a whole has decreased to below 20%. A significant proportion of disability in developing regions arises from preventable disabilities. UN statistics state that about 20% of all impairments are caused by malnutrition and over 10% by infectious diseases.

Both causes are linked strongly to poverty.

The focus on early intervention and pre- and post- natal health care tends to lead to a discussion about disability prevention, often in a way that undermines the dignity of life for people with disabilities today. Inclusion International supports the provision of health education and adequate health care for mothers and their infants in a way that is sensitive and respectful of people living with disabilities.



7



2.5 Achieving the Rights of Children with Disabilities and Families

By 2015, the rights of children with disabilities, as outline in the UN Convention on the Rights of the Child, will be respected; mothers will receive adequate pre- and post-natal health care to ensure the well being and healthy development of all children; families will get the help they need for the care and support of their family member with a disability

The UN Convention on the Rights of the Child (UNCRC) and the subsequent World Fit for Children (WFfC) represent a real commitment to the rights of children worldwide, including children with disabilities. Their purpose is to advance a world where children grow up with dignity, freedom, equality and peace.

Children who have a disability are consistently among the world's poorest and most disadvantaged children. The realization of their human rights requires strategies to promote inclusion in the home with their families, in their communities and in systems of education, early child development and health.

2.6 Combating HIV/AIDS Among People with Disabilities

By 2015, the spread of HIV\AIDS in the community of people who have a disability will begin to be reversed and children with disabilities who have been orphaned will be supported and cared for in the community

While there is little data to confirm that people with disabilities (particularly women) are more vulnerable to contracting HIV/AIDS, we know from the real experience of families and people who have a disability in Africa that conditions of extreme poverty, and poor health education result increased exposure and infection.

In many African countries there are widely held myths about AIDS including the belief that a man can be cured by having sex with a women or girl who has a disability. Efforts to stem the spread of HIV and AIDS will require health education campaigns targeted both at the population as a whole and at people who have a disability and their families. In addition, efforts are needed to identify and support the large number of children who have a disability who are orphaned as a result of AIDS.

2.7 **Ensuring Environmental Sustainability for People with Disabilities**

By 2020, achieve significant improvement in the lives of people who have an intellectual disability and their families who live in extreme poverty

UN Millenium Development Goals target the living conditions of people who live in extreme poverty and specifically the 100 million people living in slums.



The impact of living in these conditions and the poor access to health care and nutrition is that many people become disabled and in the reverse many people who are disabed end up living in these conditions because of a lack of access to education and health care supports.

Within the population of people who reside in inadequate housing, slums and shanty towns a disproportionate number are people who have a disability. Efforts to address the living conditions in these areas must include a focused accessment of the needs of people who have a disability and strategies to provide supports for them.

2.8 **Developing a Global Partnership for Development and Inclusion**

By 2015, global efforts to promote good governance and global partnerships will contribute to the human rights of people with intellectual disabilities, including citizenship and economic rights

The inclusion of people with intellectual disabilities is not only in line with the realization of basic human rights and human development, it is also a lens through which to understand and plan for the inclusion of vulnerable groups across the board.

In promoting global partnerships for economic development, the UN and world leaders have a recognized the need to base these partnerships on good governance structures and practice. The criteria for measuring good governance must include the capacity to ensure that all those who are marginalized in a society are able to benefit from global partnerships.

A model of inclusion is grounded in a rights-based approach to disability and taps into societies' most valuable norms and services. It suggests ways in which nations can be constructed to involve all citizens by engaging them in cost-effective, good quality inclusive education; by ensuring access to reasonable health care; by supporting viable employment options; by initiating a space for popular participation in political processes that seek to include isolated and marginalized voices.

The experience of people with intellectual disabilities has challenged us to think about human rights in relation to the way communities and societies are organized. In order for a person with an intellectual disability to participate in school, in their community or in a work environment, it is not sufficient to provide them with a device or aid, nor does the creation of a separate system help to achieve their rights to education, health care etc. Rather systems need to be designed (education, political participation, employment, health care) in ways that consider the needs of people with intellectual disabilities from the outset. This approach and understanding of human rights helps also to address the exclusion of other communities of people who are marginalized.

To realize real progress in the inclusion of people who have a disability in communities, human rights commitments to inclusive policies and programs, community capacity building and policy engagement processes are necessary. While human rights instruments have much to offer, on their own they have not been an effective strategy in advancing the inclusion of people with disabilities.



EXISTING COMMITMENTS TO INCLUSION & HUMAN RIGHTS

3.1 **Existing Commitments to Inclusive Education**

- The UNESCO sponsored 'Education For All' initiative, states that all children, including those with disabilities and other special needs are entitled to equity of educational opportunity
- UNESCO and the OECD have also determined that inclusion is the preferred approach to providing schooling for students with special needs. It is widely accepted that the conditions required to allow for successful inclusion are also those that contribute to overall school improvement and high levels of achievement for all children
- The G8 Task Force on Education noted that fewer than 2% of children with disabilities participate in formal education systems and recommended, "measures for disadvantaged children should be included in national education plans and that education must be inclusive.
- The World Bank is supporting research and development into models for inclusive education while also promoting inclusive practices worldwide (see Inclusive Education in Brazil press release, April 17, 2003)

3.2 **Existing Commitments to the Human Rights of Children with Disabilities**

The most prominent commitments to the rights of children with disabilities to date are:

- Article 23 of the United Nations Convention on the Rights of the Child specifically address the needs of children with disabilities: "States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community."1
- A World Fit for Children also makes specific commitments to children with disabilities: "We will take all measures to ensure the full and equal enjoyment of all human rights and fundamental freedoms, including equal access to health, education and recreational services, by children with disabilities and children

3.3 **Existing Commitments to the Human Rights of People with Disabilities**

The UN Declaration of Human Rights (1948) clearly and explicitly states that human rights are universal and indivisible therefore applicable to all human beings regardless. While this is true in theory it is often much less true in practice. Disability-specific commitments include:

- UN Declaration on the Rights of Disabled Persons
- UN Standard Rules on the Equalization of Rights for Persons with Disabilities
- Declaration on the Rights of Mentally Retarded Persons
- UN World Programme of Action concerning Disabled Persons
- Inter-American Convention on The Elimination of All Forms of Discrimination Against Persons with Disabilities (AG/RES. 1608 (XXIX-O/99)



CONCLUSION & POLICY RECOMMENDATIONS

4.1 Conclusion

The United Nations Millennium Development Goals offer a real opportunity for the inclusion of people with disabilities in developing and transition countries by outlining targeted commitments to reach some of the most vulnerable people worldwide.

4.2 Promoting Policy Dialogue on Poverty & Disability

A national and global capacity to participate in poverty reduction initiatives is fundamental to reduce the poverty of the poorest of the poor, including those with disabilities

- Participatory consultations must seek out excluded groups to ensure the inclusion of poor people with disabilities and their families
- Strategies and programs for employment creation and vocational training must include workers with disabilities as a cost-effective means of reducing their individual poverty
- Proper neighbourhood and community planning as well as support to families and family organizations facilitates the creation of stronger social networks, which in turn helps reduce the overall household poverty among families with a member with a disability
- Investing in inclusive education to ensure that children with disabilities gain a good quality education in an equal learning environment among their peers is among the strongest tools for reducing individual poverty

4.3 Promoting Policy Dialogue on Education & Disability

Delivering on commitments to achieve universal basic education for all children requires multiple strategies at the local, regional and global level:

- Monitoring of multilateral and bilateral investments in education by civil society groups to ensure that they are inclusive of children who have a disability
- Strengthening the capacity of civil society groups to contribute to public policy approaches to inclusion through participation in national planning for educational improvement
- Contributing to knowledge about both policy and practice for inclusive schooling



4.4 **Promoting Policy Dialogue on Gender & Disability**

There are few global statistics that can adequately reflect the kind of discrimination and vulnerability faced by women with disabilities and mothers that birth a child with a disability. However, through interviews and discussion with both groups Inclusion International has identified the following:

- Facilitating social networking and support for mothers who have a child with a disability
- Providing adequate information and guidance to new parents and their infant
- Raising awareness about the vulnerability and abuse of women with disabilities both in the community and specifically targeted at enabling women to know their rights
- Including in all gender monitoring the impacts of policies and programs on women with disabilities as well

4.5 **Promoting Policy Dialogue on Pre- and Post Natal Health Care**

Proper health care for pregnant women and their newborn infants has widely been identified as a fundamental necessity for infants to get a good start to life. This requires:

- Strengthening the capacity of governments to support immunization programs throughout the developing world
- Providing proper nutrition and health education for pregnant and nursing women to enable them to better care and provide for their children
- Working in multi-stakeholder coalitions to ensure the good nutrition and education of mothers worldwide
- Ensuring easy access to sound medical advice and attention

4.6 Promoting Policy Dialogue on Rights of Children with Disabilities and their **Families**

Commitment to the rights of children with disabilities begins from the community up to the global level. To realize the human rights of children with disabilities concerted action is required. For example,

- Ensure that National Plans of Action for implementing the World Fit for Children includes issues affecting children with disabilities and their families
- Develop mechanisms to connect commitments to children's rights to a public policy framework, which supports the economic, social, political and cultural rights of all children



Raise awareness among children's advocates across the board and strengthen their capacity to take on issues affecting children with disabilities in their work

4.7 Promoting Policy Dialogue on HIV/AIDS & Disability

Initiatives intended to reduce the spread of HIV/AIDS and improve the quality of life of both those living with the virus and those impacted by the disease (orphans, etc) need to target people with disabilities who are both very vulnerable to abuse, engage in intimate relationships themselves, and are more likely to be ignored or forgotten should key family members succumb to the disease. To adequately address these concerns efforts must go towards:

- Developing plain language materials and tools and ensuring that people with disabilities are aware of the disease and how best to protect themselves from contracting it
- Targeting strategies and programmes geared towards curbing infection rate at people with disabilities
- Ensuring that orphans with disabilities are found appropriate housing in their community with a family, preferably with their extended family - family must be given adequate supports to care for the child as would his/her natural parents

4.8 Promoting Policy Dialogue on Human Rights & Disability

Considering the emerging challenges of a new economy, the limitations of our human rights instruments, and the limitations of current disability-related investments in enabling inclusion, what strategies can be used globally to advance the human rights and inclusion of people who have a disability in our societies?

There are four broad and inter-related elements of a strategy to advance peace and inclusion in a way that builds upon human rights commitments and strategies. These are:

- Establishing an inclusive policy framework: Shifting from "disability policy" to "inclusive policy" is a critical step in realizing the human rights of people who have a disability. In order for societies to value and respect the contributions of people who have a disability, political, economic and social policies must be designed to be inclusive.
- Investing in the capacity of civil society: Practically, this requires the strengthening of new skills, visions, strategies and processes for Civil Society Organizations to become actively engaged in transforming public policy. Too often approaches to building capacity have focused on

"I have learnt that discrimination and segregation can become an accepted part of community life. Our parents begin to accept that it is right. Even those of us with the disability begin to accept that it is right. "Everyone is in their rightful place and the community begins to congratulate itself on how it cares for the less fortunate". "Don't they have a wonderful place to live, don't they have wonderful staff and don't we spend a lot of our money caring for the unfortunates", they say.

I would ask one simple question. If it is so wonderful why doesn't everyone want to grow up like I did (in an institution)?"

> Robert Martin To view full speech visit www.inclusion-international.org



infrastructure and tasks that ultimately result in altering the purpose and substance of grassroots groups.

- Creating policy dialogue: Strategies to advance inclusion must include the establishment of processes and forums which take advantage of the knowledge that exists in communities by building on and scaling up from existing local, grassroots and civil society development activities, experiences and knowledge. The processes must link the knowledge of communities to policy development, implementation and monitoring by governments and international institutions.
- <u>Developing global knowledge networks</u>: In advancing a global agenda for inclusion there are multiple stakeholders who possess knowledge about policy systems and processes, community development, human rights instruments, research and global economies. Some of this knowledge is shared between members of a stakeholder group (i.e. researchers share information with researchers), however, there are significant gaps in transferring knowledge; translating knowledge into tools and using knowledge to advance an agenda for inclusion.

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Studying with his Peers, India



Mother with Child, Nicaragua



Promoting the Value of All People as Equals

- All people are people first and must be treated with dignity and respect and be accepted.
- Each person must be recognised as the person they are.
- All individuals must have the right to make their own decisions and to have these decisions respected.
- From birth, every human has the same worth.
- All people have the right to be valued as an equal in their own community.

From, "The Beliefs, Values and Principals of Self-Advocacy" (ILSMH 1994)

This statement expresses an unequivocal demand by people with an intellectual disability to be treated as equals. However the reality has been that with the exception of a small number of communities, the lives of people with an intellectual disability have been marginalized, devalued and all too often abused.

The lives of adults with an intellectual disability are all too often stigmatized by poverty, little or poor education, poor health care, poor housing and segregation from mainstream community life.

People with an intellectual disability are grossly over represented in areas such as institutional care, discrimination in housing, unemployment and abuse.

Some people with an intellectual disability lack the basic necessities of life being food, shelter and health care. A civil society can no longer accept that some people with an intellectual disability will die from the effects of malnutrition, lack of health care or neglect.

If all people are to live as equals in society we must:

- Strengthen current human rights instruments and conventions to ensure it becomes unacceptable for communities to devalue the lives of people with an intellectual disability.
- Strengthen the monitoring of these human rights instruments and conventions to ensure that all people regardless of any disability or care needs are valued as equals.
- Support the development of community life that is inclusive for all people regardless of their health status, care needs and ability to participate in the wider life of the community.