

# Chronic Poverty and Disability

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## Chronic Poverty and Disability

### Glossary and explanation of terms

**Impairment:** An individual's condition – physical, sensory, intellectual or behavioural.

**Disability:** A complex system of social restrictions imposed on people with impairments resulting in a denial of rights and equal opportunities.

**Disabled people or people with disabilities:** The chosen terminology of the disability movement varies between cultures and languages. In this document we have used disabled people, as this is favoured in the UK. However in other countries the disability movement prefers - people with disabilities. In ADD programmes we adopt the terminology favoured locally.

**Inclusive Policies:** Policies which acknowledge that socially excluded, poor or vulnerable people are not a homogeneous group and that disabled people have a right to be included in poverty alleviation and development work.

**Chronic Poverty:** For these purposes, chronic poverty is defined as those who are inter-generationally poor and also experience multi-dimensional poverty (income, education, social capital etc.).

**The South** - used in this document to denote developing countries

**The North** - used in this document to denote developed countries

**Self- Help groups** - groups and organisations which come together to address the causes of their oppression, discrimination or poverty and to advocate for inclusion.

### **Models of Disability -**

**Medical Model:** Disabled people are defined by their impairment and medical/technical solutions offered to alleviate their impairment – an individualistic approach that does not look at social barriers.

**Charity Model:** Disabled are to be pitied and helped by welfare approaches. There is no recognition of equal rights or the role that discrimination plays.

**Social Model:** This rights based model sees disability as the social consequence of having an impairment and realises that the inequities faced by disabled people can only be overcome if society becomes inclusive.

### **Types of discrimination -**

The Social Model identifies three types of discrimination faced by disabled individuals:

- **Institutional discrimination.** Institutional discrimination exists in many different guises, for example: many NGOs make no attempts to include disabled people in their work; in many countries disabled children are not required to go to school and there is no special provision for their needs if they do enroll; banks often do not accept disabled customers; employers often will not consider disabled applicants; and families do not include them in the distribution of inheritance.
- **Environmental discrimination:** In most countries the physical environment excludes disabled people. This has been referred to as apartheid by design (Imrie, 1996). Buildings with steps and narrow entrances, inaccessible "public" transport, a scarcity of information transcribed into Braille or available on audio tape and a lack of Sign-Language translators all serve to keep disabled people out, pushed to the margins and without the information they need to participate equally.
- **Attitudinal discrimination:** Prevailing attitudes are the third aspect of the disablement. There are many possible justifications for excluding and ostracising disabled people and their families. Some of the most common are beliefs that disability must be associated with evil, witchcraft or infidelity. There is confusion between illness and disability that can lead to suffocating overprotection and exclusion of disabled people from everyday challenges. Low expectations of disabled people are often held by wider society as well as by themselves.

Institutional discrimination builds and reinforces attitudinal discrimination and condones environmental discrimination. In many cases, people know that the law requires them to send their primary aged children to school, except their disabled children; bus drivers can throw disabled passengers off the bus with impunity or charge extra for carrying wheelchairs; and bank managers can refuse disabled people an account, simply because they are disabled. This leads to the general perception that these actions are valid. Together they have a logic and people use their fears, suspicions and prejudices to build a supporting rationale. Negative attitudes prevent spending on the necessary measures to overcome an inaccessible environment.

## Chronic Poverty and Disability

***'Poverty is not simply the consequence of a lack of resources. Some people are unable to access existing resources because of who they are what they believe or where they live. Such discrimination is a form of exclusion and a cause of poverty'. (DFID 2000e).***

***'Because disability and poverty are inextricably linked, poverty can never be eradicated until disabled people enjoy equal rights with non-disabled people'. (Lee, 1999)***

### **Abstract**

Disabled people are estimated to make up approximately 10% of any population (WHO) and a higher proportion of those living in chronic poverty. There has recently been a call for more information relating to disability and chronic poverty. This is due to the realisation that disabled people are disproportionately amongst the poorest of the poor in all parts of the world, and that international development targets are unlikely to be met without including disabled people. In the poorest countries of the world, particularly where there is no benefit system, being amongst the very poorest has more severe implications of life or death than in richer countries. The basic cause of this poverty is exclusion: exclusion from social, economic and political life. The industrialised north is not exempt from this exclusion. In the UK, in 1998-1999 only 1 third of disabled adults of working age were in employment (Labour Force Survey - winter 1998-1999).

In 1996, the Development Assistance Committee of the Organisation of Economic Cooperation and Development (OECD) agreed seven international development targets. These include the aim to halve the number of people living in extreme poverty by 2015, together with targets towards achieving gender equality, reducing infant and maternal mortality rates and achieving universal primary education. It is unlikely that any of these targets can be met without considering the needs of disabled people. Indeed achieving universal primary education would be impossible without including disabled people. However, whilst there has recently been a shift by some NGOs, donors, and governments towards considering the issues of disability rights in their rhetoric, disabled people in many parts of the world, have seen little change in terms of concrete action.

Whilst the international development targets with their strong focus on poverty reduction would seem a positive approach, there are several dangers of the current strategy. The targets could result in focussing on those it is easiest to bring out of poverty, not those in chronic poverty, among whom disabled people are disproportionately represented. A strategy based on economic growth and trade will not be widely beneficial to disabled people who, through discriminatory processes, are largely excluded from the labour market altogether. If current strategies are continued, then in the unlikely event that any of the targets are met, disabled people would become even more disproportionately represented amongst those living in chronic poverty. There is then a further danger that the remaining level poverty would become accepted as an inevitable fact of life.

Disabled people are so severely excluded from all areas of society that there is not even comparable or reliable data on incidence, distribution and trends of disability, let alone the extent of disabled people's poverty. What little research does exist has been done

overwhelmingly by European or North American non-disabled academics. There has been little opportunity for influence of the agenda by any disabled people, let alone those living in chronic poverty themselves.

Despite this lack of comparable data there is plenty of anecdotal and more substantiated evidence to show that disabled people are generally amongst the poorest of the poor. It is already known that: living in poverty increases the likelihood of getting an impairment; disabled people generally experience higher rates of poverty as a result of being disabled; and that when people living in poverty become disabled they are often more severely marginalised than are wealthier people.

Clare Short writes of the value of good statistics as a basis for creating the will to reduce world poverty: 'Much work is needed to improve the collection of reliable and comparative data and to strengthen local statistical capacity' (DFID, 2000b). However it is important that the focus of research is on practical benefits for reducing the chronic poverty faced by disabled people, not just on gathering data to prove something that is already well known. Depending on how it is carried out, the process of gathering statistics may help to motivate people, to assess progress and even to challenge the very exclusion that causes chronic poverty

## **1 Review of what is known about the incidence, distribution and trends of disability in the developing world, and how these relate to chronic poverty.**

There is little internationally comparable information on the incidence, distribution and trends of disability or impairments. This is one aspect of the very exclusion that defines disability. There are several reasons for this lack of information:

- a) Disabled people are so excluded as not to be considered even worthy of research. Where research has been done, it has often been done by Northern non-disabled academics. Disabled people may be used in the research but this is often done to add legitimacy to the work, rather than really allowing disabled people to control or influence the agenda. The results therefore often miss disabled people's real main issues or concerns. Sue Stubbs, (from Save the Children Fund) cites that out of 180 publications, two thirds were written by Northern writers and only 5 authors stated that they were disabled people. (Stubbs, 1999). Disabled people are disproportionately amongst those living in chronic poverty because they are often not included in any aspect of regular community life, let alone research projects. The more severely people are marginalised the less likely it is that policy makers will have reliable information about their lives. This is true whether or not somebody is disabled. As disabled people are among the most severely marginalised people in the world they are also among those least represented by any research.
- b) What research has been done uses different definitions of disability and impairment (see page 3-4) and therefore makes comparison difficult. It is proposed that any future research is based on the social model of disability that recognises disability as a human rights issue of marginalisation and exclusion. This is the definition adopted by the International Disability Movement.
- c) The UN Disability Statistic's Compendium (DISTAT) notes that disability rates are not comparable across the world because of differences in survey design, definitions, concepts and methods. Furthermore there are cultural variations on what types of impairment lead to marginalisation and exclusion. Not all impairments cause disability. For example, short-sightedness is an impairment, however in societies where glasses are easily available and socially acceptable, being short-sighted does not lead to exclusion and therefore not to disability. Similarly the level of exclusion and poverty relating to an acquired physical impairment is likely to be very different for wealthy office executives compared with subsistence farmers depending on their own labour for survival (Elwan, 1999).
- d) As disabled people are frequently excluded from all manner of social, economic and political interactions they have generally not been powerful enough to exert an influence on policy makers. Gathering reliable data on disability has never been a high priority amongst policy makers. The UNDP and the World Bank produce regular Development Reports with information on many different aspects of life. Neither organisation mentions disability.
- e) The very marginalisation that disabled people face makes it difficult for outside researchers to find them and to communicate with them even if the researchers want to. There are several reasons for this: in areas where stigma is attached to having a disabled person in the family, other members of the family may deny the existence of their relative; disabled people may not physically be able to get to community meeting places e.g. schools, churches, health centres or trading places; or may be socially excluded from these places.
- f) Methods of research often exclude people with many forms of impairment. Participatory Rural Appraisal is becoming an increasingly popular research method.

However it tends to be very visual and therefore excludes people with visual impairments. Radio is inappropriate for deaf people. Many disabled people have been excluded from all formal education and therefore rates of illiteracy are even higher than among the wider group of those living in chronic poverty. A study in Bahrain in 1981 found that 27% of the population over 10 years of age were illiterate compared with 77% of disabled people (Elwan, 1999 citing DISTAT, 1990, table 6). Therefore written surveys are generally inappropriate.

- g) Disability is often considered a specialist issue separate from mainstream development issues. Many mainstream development NGOs still say that they are not 'specialists' and therefore do not consider disability issues. However, most disability issues are important to all development: equality, empowerment, human rights, poverty and marginalisation (Lee, 1999).

### Existing Studies

In 1990 the United Nations created the Disabilities Statistics Database (DISTAT). This was an attempt to gather together national disability statistics in order to form global comparisons. According to DISTAT, in 1990 the proportion of disabled people per national population varied between less than 1% in Peru and 21% in Austria (DISTAT 1990). However this database uses no agreed definitions of disability, impairment or forms of research. Therefore these statistics are both unreliable and incomparable.

In 1981 UN/WHO studies estimated that on average 10% of national populations are disabled. However in 1992, this estimate was modified to 4% for developing countries and 7% for industrialised countries (Metts, 2000). The UNDP estimates a global proportion of disabled people of 5% (Coleridge, 1993). There is no consensus as to which figures to use: USAID use 10%, DFID use 4-7%. These figures are all rough estimates based largely on incomparable information, with no consideration of cultural variations in the level of exclusion relating to different impairments. For example, dyslexia is included in the definition of disability used by the WHO. The extent to which dyslexia leads to disability in a country where the majority of people are illiterate is questionable.

Where statistics have been gathered, it is generally reported that there is a higher proportion of disabled people in richer, more industrialised countries, than in poorer countries. The probable reasons for this are that in more industrialised countries there is: greater detection and therefore more accurate statistics; better medical treatment leading to higher survival rates and greater life expectancy with associated age-related impairments. In more rural-based economies it may be easier for disabled people to stay hidden from the view of outsiders. It is generally the case that, where possible, people will not define themselves as disabled to outside researchers unless there is some advantage in doing so. It is therefore often only those disabled people who are openly visible who are included in surveys. In richer industrialised countries where social security benefits are available, there is more reason to identify oneself as a disabled person.

What information on disability and poverty that does exist is largely based on anecdotal evidence. Whilst not all disabled people are poor, evidence points to a disproportionate number of disabled people in all countries being amongst those living in extreme or chronic poverty. Recent World Bank studies contend that "half a billion disabled people are undisputedly amongst the poorest of the poor" (Metts, 2000) and are estimated to comprise "15 to 20% of the poorest in developing countries" (Elwan, 1999). This is



considerably higher than estimated figures for the proportion of disabled people in society as a whole.

Whatever the motivation of individual researchers, it is extremely difficult to get accurate or comparable statistics on disability in isolation from changing the attitudes of policy makers or the wider community. In India, progress has recently been made in terms of gathering data. The disability movement successfully lobbied for two questions regarding disability to be included in the 2001 census (see section 3 for Indian case study). The very fact of including these questions is a step towards reducing the marginalisation that disabled people experience. It is important that the need for accurate and comparable statistics on disability issues is not seen as a separate task from actually tackling the chronic poverty and exclusion that causes disability.

## **2 The social, economic, political and other causes of chronic poverty among disabled people**

The relationship between disability and chronic poverty varies within and between cultures. Although disabled people are disproportionately amongst those living in chronic poverty and all disabled people experience discrimination, not all disabled people are poor in economic terms. Poverty is not only about rates of income but also about social exclusion and powerlessness. Simon Maxwell (1998) writes that people become poor because they are excluded from social institutions where access is based on status, privilege, race and gender. Exclusion leads to lack of resources, lower expectations, poor health and poor education. For these purposes, we are looking at those disabled people who experience chronic poverty in terms of income, as well as wider social exclusion.

### **High rates of chronic poverty among disabled people (see table 1)**

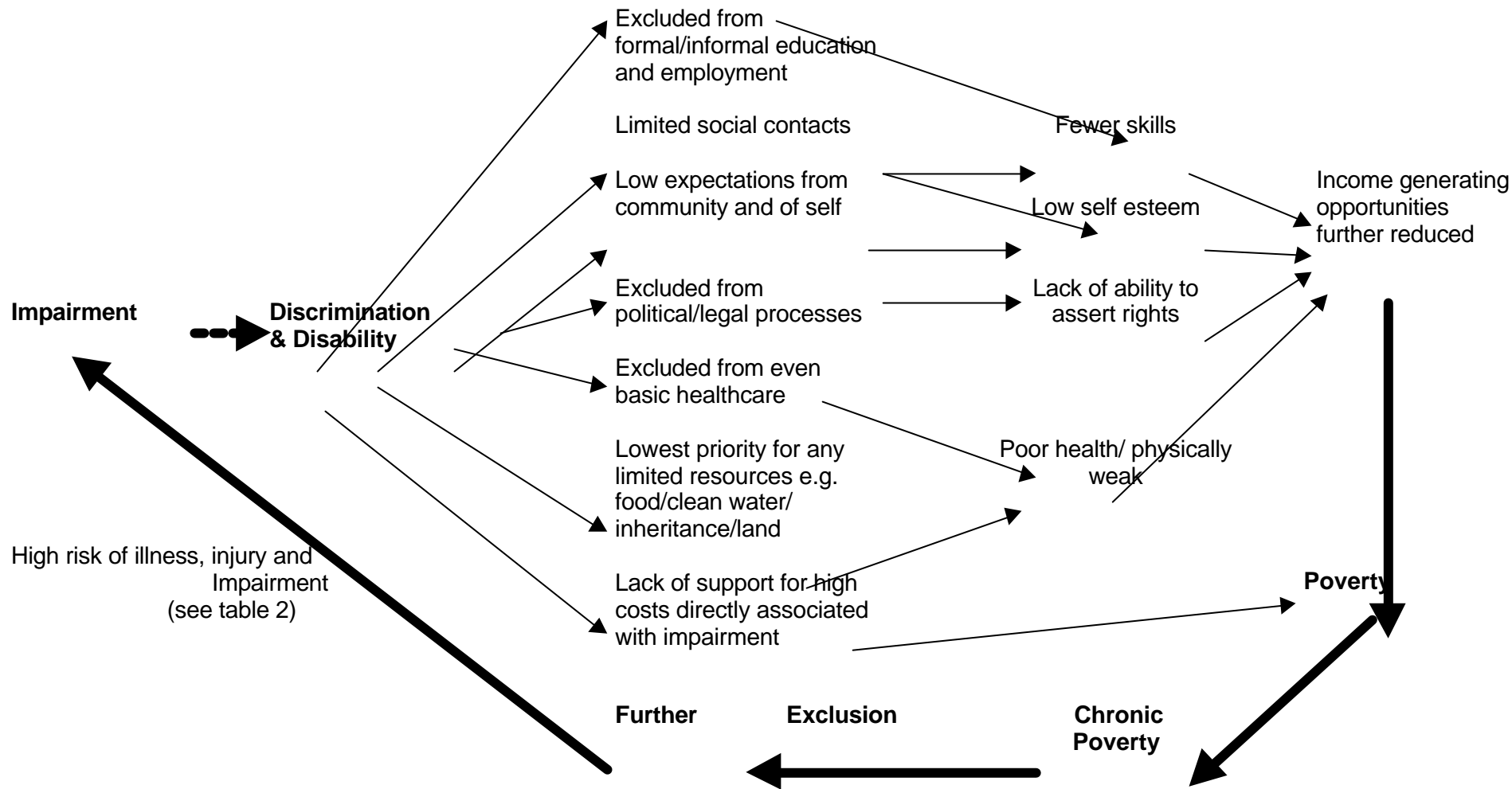
Disabled people experience discrimination from birth, or from the moment of becoming disabled, onwards. The birth of a disabled child is often considered a tragedy. The child needs more care and may not be considered to have the potential to support him or herself, let alone the older generation, in the future. In communities that are already living in chronic poverty, disabled children may be excluded even further. Where there are limited resources it may be seen as economically irresponsible to give an equal share of resources to a disabled child who is perceived as unlikely to be able to provide for the family in the future. "Early lack of investment in disabled children is not just a reflection of ignorance. In situations of poverty this is a desperate but rational decision" (Ashton, 1999).

Disabled children often get last access to food and other basic resources. When disabled children get ill they are often not given treatment but left to the "hand of God". They are less likely to be sent to school (even if physically possible), for fear that: they will not cope; or that their disclosure will stigmatise the family and affect the marriage prospects of siblings; or that they are not a worthwhile investment and others should get priority. The International Disability and Development Consortium estimate that 98% of disabled children in developing countries are denied any formal education (IDDC, 1999). Those children who do get education often get inferior treatment, have low expectations of themselves and from others and do not get the support they need in order to participate equally. Disabled children often have fewer demands placed on them, and therefore may learn less than non-disabled siblings even in an informal setting. Right

from the start they are excluded from many of the day-to-day interactions that non-disabled children take for granted.

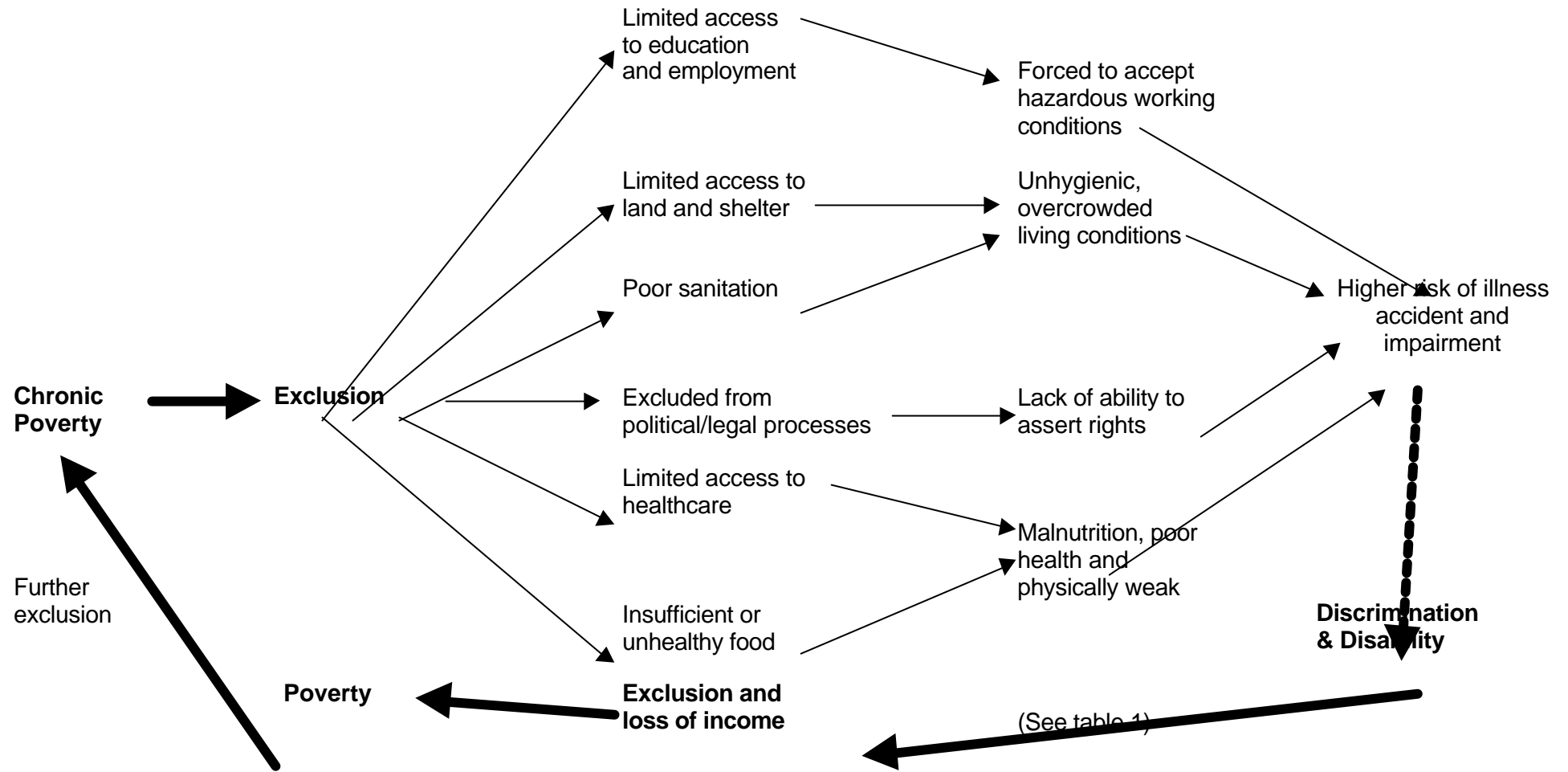
Many disabled children become street children. In some cases, impairments are intentionally created for begging purposes. Despite the high proportion of disabled children living on the street they are frequently excluded from programmes working with street children, as disability is seen as a specialist issue.

**Table 1: Disability/Chronic Poverty Cycle**





**Table 2: Chronic Poverty/Disability Cycle**





For all these reasons, as well as the direct result of impairment, many disabled children do not survive, particularly those born in poorer communities. Of those children that do survive, they are at a huge disadvantage as they grow-up having been excluded from formal and informal education. This has an impact not only on qualifications and experience but also on levels of confidence and self-esteem. Later in life, disabled people have restricted employment opportunities, due to discrimination, lack of education, experience and confidence. If, during childhood, disabled children are not included in the community, then as they grow up, their non-disabled peers may not be aware of their existence, let alone their value and rights as equal citizens. In addition to this a disabled person often faces high costs directly resulting from the impairment. In a survey in India it was found that the direct cost of treatment and equipment for a disabled person varied from the equivalent of 3 days to 2 years income (Harriss-White cited in Elwan, 1999).

Excluded from mainstream social, economic and political opportunities throughout their lives, disabled people frequently fall further and further into chronic poverty and have little opportunity to come out of this cycle. Even those organisations purporting to work on chronic poverty issues frequently (intentionally, or unintentionally) exclude disabled people.

If from birth onwards, disabled people are not given the resources and access they need to participate, then, “to assume that this group is a drain on society becomes a self-fulfilling prophecy” (Groce, Chamie & Me, 2000). It is still frequently not recognised that people are, “disabled from participating by others’ attitudes and social barriers... Many people still believe that disabled people are not able to participate” (Hurst, 1999).

Where the main breadwinner of the family becomes disabled it often has a devastating effect on the whole of the family. The whole household may slide deeper into poverty. Changing power relations and allowing disabled people to contribute could help reduce the poverty of the whole community.

### **Chronic poverty causes higher rates of impairments (see table 2)**

Not only do disabled people experience disproportionately high rates of poverty, but being poor dramatically increases the likelihood of getting an impairment. Those living in chronic poverty often have limited access to land, healthcare, healthy food, shelter, education and employment. Furthermore people in chronic poverty often have to put up with hazardous working conditions. All these factors can cause illness, injury and impairments.

It is estimated that one hundred million people worldwide have impairments which are caused by malnutrition and poor sanitation and are therefore preventable (Lee, 1999). The World Health Organisation (1992) estimates that up to 70% of childhood blindness and 50% of hearing impairment in Africa and Asia are preventable or treatable (ibid). In India, lathyrism is a motor-neurone disease that affects mobility and coordination. It is caused by toxins in the cheapest forms of lentils. Almost everyone eating these lentils is aware of the risk, but has no alternative. In Cambodia it is estimated that over 70% of recent landmine survivors had been farming or foraging with the full knowledge that they were doing so in areas infested with landmines (Action on Disability and Development, 1997).

There is a vicious circle. Chronic poverty often leads to higher risk of impairment. The impairment can then lead to more marginalisation and exclusion, resulting in disability, more exclusion, loss of income and further poverty. Many elements of this cycle are inevitably inter-linked. However impairment does not inevitably lead to discrimination and disability. It is at this point that the cycle could be broken.

### **3 Action being taken to reduce the chronic poverty among disabled people**

During the course of this century many different groups and organisations, in different parts of the world, have claimed to be working on behalf of disabled people. Generally this has been either: through exclusion, segregation and patronising welfare programmes (the charity model); or, through attempts to "cure" the individual disabled person (the medical model); or, most commonly, a mixture of the two. There has been little recognition of disabled people having equal rights, or of the barriers that are faced (the social model).

Governments, development agencies and service providers have frequently, either ignored disabled people or, created 'special' expensive programmes that effectively exclude disabled people from mainstream society. These programmes generally only reach small numbers of those disabled people in capital cities with no consideration for the needs of the vast majority of rural-based disabled people. Charities have overwhelmingly adopted patronising and disempowering ways of working with disabled people. Medical professionals have predominantly worked to try to find a 'cure' and to make disabled people appear as similar as possible to non-disabled people. Family and friends have often kept disabled people hidden or over-protected.

The disability rights movement began in the 1960's and 1970's. This is gradually leading to a shift of emphasis on disability policy. In a UN survey of 79 member states in 1995/96, 69 countries reported having officially recognised disability policies (Metts, 2000: 20-23). Many NGOs and donors (for example: USAID, DFID, Oxfam, SCF) are also now changing their approach and are claiming to be including disabled people in their poverty reduction work. The change in approach is motivated partly by awareness of the high economic costs of exclusion and partly by the focus on achieving international development targets. As DFID (2000a) write, "given the high proportion of people with disabilities among the poor, it is unlikely that these targets can be properly achieved without specific efforts to tackle disability".

The impact that the change in rhetoric has on the chronic poverty faced by disabled people is however minimal in most cases. Participants at a regional seminar of the Economic and Social Commission for Asia and the Pacific (ESCAP, 1999) on Poverty Alleviation among Rural Persons with Disabilities noted that, in some parts: "the number of people living below the poverty line had been halved over the past several years. However, even though rural disabled persons were the poorest among the poor, they had not been included in the mainstream rural poverty alleviation programmes in most of the countries". Until the barriers that disabled people face are recognised and addressed, there can be no substantive or sustainable change in the marginalisation and chronic poverty experienced.

Whilst the exclusion and discrimination faced by disabled people bears many similarities to racism and sexism there is an important fundamental difference. There is an element



of reduced capabilities for people with some forms of impairments. This is sometimes used as a justification for exclusion. Unless additional practical needs are met, it is difficult for some disabled people to campaign, to exert influence and to work to reduce their own chronic poverty.

Whilst recognising the potential economic gains of inclusion, it is important for any organisation (state, NGO, donor or business) to recognise that investment is required. To make inclusion meaningful, all staff need to be trained in disability equality issues. Individual disabled people may have specific access requirements that need to be met before full participation is possible. Unless these costs are met, then inclusion may be nothing more than a theoretical concept. Disabled people may become involved in an organisation without being able to fully participate. This can then lead to confirmation of preconceptions about disabled people's lack of abilities. Such token involvement does little to reduce the marginalisation experienced by disabled people.

There are global similarities in the exclusion faced by disabled people. "There is no country in the world where disabled people's rights are not violated. The discrimination, oppression, violence and abuse faced by disabled people does not respect national boundaries, national wealth or national poverty" (Hurst, 1999). There are also many differences in the ways in which disabled people are organising and the influence that they have on policy makers. Specific case studies of Uganda and India will be considered after having looked at the role of different actors in more global terms.

### **International organisations**

Many international organisations claim to be taking disabled people's needs into account: the WHO promotes a medical rehabilitation approach to disability issues; UNESCO promotes inclusive education policies; the ILO has adopted the rhetoric of including disabled people in their employment work; UNICEF focuses on prevention of impairment in children through health and immunisation programmes. However, disabled people themselves are rarely involved in the policy making of these organisations. This makes it extremely difficult to form effective strategies of full inclusion.

According to Robert Metts (World Bank, 2000) the lack of comparable information on disability and chronic poverty makes it difficult for the World Bank and other international organisations to form cost-effective disability policies or to evaluate different approaches towards tackling chronic poverty and disability. In 1993, the World Bank developed an international classification system known as Disability Adjusted Life Years (DALY). The stated aim of DALY was to provide internationally comparable data on the global burden of disease and disability in order to prioritise health needs. The assumptions behind DALY are that disabled people represent a drain on society; that disability can be measured in terms of years of burden and loss; and that disability and disease are synonymous. There is no recognition of the discrimination and marginalisation faced by disabled people, nor consideration of the cultural context of different impairments. An impairment is given the same value, irrespective of any cultural context or level of exclusion experienced as a result of the impairment.

The WHO has developed a different system. In 1980, it introduced the International Classification of Impairment, Disability and Handicap (ICADH). This was seen as extremely progressive at the time, as it incorporated some social and environmental factors into definitions of disability. More recently, in 1997, the ICADH-2 was developed.

This goes further towards recognising that a disabled person may have an impairment, but would not inevitably have significant limitation of activities if exclusion and discrimination were not experienced.

These classification systems may go some way towards providing comparable statistics. But unless the inequalities in power relations, the discrimination and the exclusion faced by disabled people are addressed, then these systems will not help to tackle chronic poverty. A willingness to include disabled people in these institutions is needed.

In terms of action by international organisations, the most significant has been by the UN. In 1982, the UN introduced a World Programme of Action concerning disabled persons (WPA). The aim of this was 'to promote effective measures for prevention of disability, rehabilitation and "full participation" of disabled persons'. Then began the International Decade of Disabled People (1982-1991). This was followed by the Asian and Pacific Decade (1993-2002) and the African Decade (2000-2010). These all serve to raise awareness and focus attention. In 1993 the UN introduced the Standard Rules on the Equalisation of Opportunities for People with Disabilities (see annex). These were agreed by all member states of the UN. They are not legally enforceable, but do set an anti-discriminatory and inclusive international standard. Several countries, and organisations within them, have used these Standard Rules to influence their approach to disability.

### **Governments**

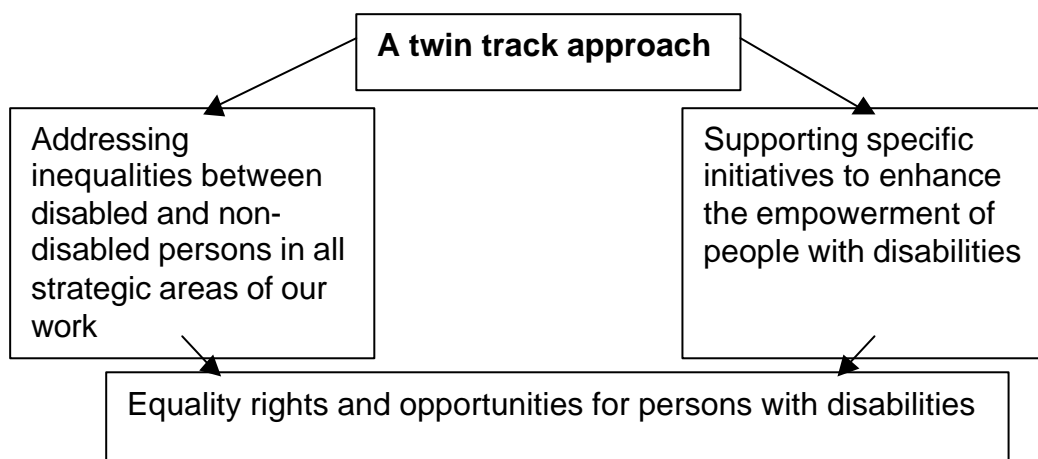
During the last decade, many governments introduced some form of legislation against disability discrimination (USA 1990; Zimbabwe 1992; Australia 1993; India 1995; Bangladesh 2001). The Indian Persons with Disability Act is based around the UN Standard Rules, however it uses a very medical definition of disability to determine who can benefit from the Act (see [www.disabilityactindia.org](http://www.disabilityactindia.org) and case study on India pages 28-32 for more details). Despite the WPA and the Standard Rules, the emphasis of most national disability policies is still on disability prevention, rehabilitation and individual support rather than on anti-discrimination and rights based legislation.

In most countries, government services for disabled people are still small-scale rehabilitation projects separated from the rest of the community. These are extremely high cost, meet the needs of only a few disabled people and do not address the underlying causes of chronic poverty: exclusion and lack of equal rights.

Few governments have taken, and implemented, a disability rights-focused approach to social, economic and political inclusion. The main motivation for governments that do introduce inclusive approaches to working with disabled people has generally been economic. There is growing recognition of the high economic costs of exclusion. If disabled people are unable to contribute to society then they will inevitably be an economic burden on others. The economic reason to include disabled people is particularly strong in areas of the world where HIV/Aids is devastating the most productive sector of the economy. It is through inclusion that chronic poverty can be addressed. In Zimbabwe, for example, less than 1% of disabled people are thought to actively contribute to the economy (Lee, 1999).

The British Department for International Development has recognised that, 'disability is a major cause of social exclusion, and is both the cause and consequence of poverty'

(DFID 2000d). DFID recently published an issues paper, entitled Disability, Poverty and Development (2000a). This called for a twin-track approach:



In this, DfID call for the inequalities between disabled and non-disabled people to be recognised in all areas of their work as well as supporting specific initiatives with disabled people. This recognises the fact that disabled people often do have specific needs to be met in addition to those of other people living in chronic poverty. Therefore there is the need for specific initiatives working with disabled people as well as for disability issues to be included in all areas of work. There is also recognition that it is unlikely that international development targets will be met if disabled people continue to be excluded.

South Africa has developed a high profile, crosscutting approach to disability issues. The Office of the Status of Disabled People is in the President's office with ready access to Ministers.

The Ugandan government is widely considered the world leader in terms of political empowerment of disabled people (see case study). However, even in Uganda, disabled people are still severely marginalised and amongst the very poorest of the poor. A positive approach in government rhetoric is not enough to change the situation alone. However, full participation of disabled people in government could cause major changes in all areas.

### **Non-Governmental Organisations (NGOs) and Donors**

Most NGOs and donors have also focused predominantly on the medical or charity models of disability. The emphasis has been on providing medical aids rather than looking at the social and attitudinal causes of chronic poverty among disabled people. Almost no mainstream NGOs had even considered including disabled people in their development work until the late 1990s.

There are, in any case, several limitations in relying on NGOs to meet the needs of disabled people. "First, they have relatively small and insecure funding. Second, their provision is unsystematic and discretionary. Third, they are minimally regulated; redress by disabled people for incompetence is practically impossible to obtain" (Harriss-White, 1999).

There are specific impairment organisations working in developing countries e.g. Sound Seekers (working with deaf people internationally), Sightsavers (working with people

with visual impairments), Handicap International (provision of artificial limbs). All these organisations have traditionally worked predominantly on a medical model of disability. Their focus is on 'cure' and prevention of impairment, rather than issues of exclusion and chronic poverty. It may be that these organisations provide the means for disabled people to then access mainstream development. However, this assumes that other development organisations are receptive to disabled people.

Most mainstream development NGOs; still do not have an inclusive approach to working with disabled people. Many organisations still consider disability a specialist issue that they are not qualified to address. Others claim to work for the whole community, whilst giving little, or no, consideration to the access requirements of disabled people. In practice, this also excludes disabled people. These approaches are still widely considered acceptable, whereas advertently making no attempt to include women in development work would no longer be considered justifiable.

Some organisations are now working to become more inclusive. Save the Children and Oxfam both now aim to follow a twin-track approach towards disability, in a similar way to DFID. PLAN International now has a directive to all country programmes that at least 10% of all beneficiaries should be disabled people. The extent to which these new policies are carried out in practice is yet to be realised. USAID have a policy of including disabled people, however this is generally in specific groups rather than in all areas of work.

**Action on Disability and Development (ADD):** ADD was set up in 1985 to provide an inclusive approach to development and disability. ADD works in 12 countries across Africa and Asia supporting disabled people to form and strengthen their organisations and to fight for their inclusion in all aspects of society. ADD also works to influence government, NGOs and service providers to adopt a more inclusive approach towards disability and development. ADD is the only British-based development organisation working exclusively with disabled people, using a rights-based approach. See [www.add.org.uk](http://www.add.org.uk) for an overview of ADD's work.

**Save the Children Fund (SCF):** SCF was involved with ADD in helping to develop DFID's disability strategy. There has been a shift within SCF towards seeing disability as a development issue involving the whole community rather than an individual rehabilitation issue. The main objectives of SCF's disability strategy are that disabled children's rights should be included as components of the policies and practices of all the relevant agencies, and that a disability perspective should be integrated into SCF's work at all levels. SCF aims to follow a twin-track approach, supporting specific disability programmes as well as integrating a disability perspective into all of its work.

**Disability Awareness in Action (DAA):**

DAA provides an information network for disabled people and their organisations worldwide, to support their self-help activities and to ensure their equality of opportunity. DAA produces a number of training manuals on such issues as working with the media, group formation, disabled women etc. Their newsletter Disability Tribune is available in a range of languages and formats and through their web-site and has worldwide distribution. <http://ourworld.compuserve.com>

### **Corporate Sector**

The power of the corporate sector has grown in relation to governments. It has therefore become increasingly important to consider how the actions of this sector affect disabled people's capacity to escape chronic poverty. Disabled people are currently so disproportionately amongst those living in chronic poverty, that few have the disposable income necessary to make inclusive approaches appear viable to many businesses. The long-term effects of exclusion mean that many entrepreneurs may not even be aware of the existence of disabled people as potential customers.

There has been a shift of emphasis in many parts of the world towards encouraging businesses to increase the employment of disabled people. At the start of this century there was a focus on state-run institutions. This changed to a preference for sheltered employment schemes. There is now increased rhetoric of more mainstream inclusive employment policies. These current policies do not generally however, take account of the institutional discrimination inherent in markets as they now exist. As Barbara Harriss-White writes, "Market-based provision is largely inappropriate as a response to conditions of disability. This is for three reasons. First, markets respond to purchasing power rather than to need. Second, markets are everywhere deeply embedded in social institutions of prejudice and discrimination. Third, firms comprising markets and competing in them cannot be expected, unaided by the state, voluntarily to add to their cost by adapting workplace sites so as to accommodate disabled workers" (1999). Similarly, current strategies for development through increased trade and economic growth, will do little for disabled people if the discrimination widely excluding disabled people from the labour market is not also addressed.

ADD works with organisations of disabled people and has supported many to build up their own businesses. Small-scale credit and vocational training has been provided. It is recognised that this is not viable as a long-term strategy. Therefore, the approach is based on building examples of successful businesses in order to influence mainstream credit providers of the credit worthiness of disabled people.

### **Disabled People's Organisations (DPOs)**

One of the ways in which disabled people are excluded is that they often have little contact with other disabled people in their own country, let alone in other parts of the world. This leads to isolation and lack of ability to learn from others' experiences. Disabled people have therefore recognised the need to form organisations able to network with each other and to influence decision-makers.

Organisations are always more effective at influencing decision-makers, than individuals would be alone. This is particularly the case where people are also fighting starvation, segregation and isolation. Individually, many disabled people do not have the energy or resources to campaign for inclusion. DFID recently recognised a need to support 'initiatives which enhance the skills and capacity of poor people to organise into associations and alliances in order to participate in decision making processes' (DFID 2000e).

Disabled people around the world are increasingly forming organisations to represent their needs and to lobby for change. The number and effectiveness of these organisations varies within and between countries. In some areas these are becoming recognised and consulted as legitimate representative bodies. Through these organisations, disabled people have, in some cases, gained access to the political

process. For example the National Union of Disabled People of Uganda successfully lobbied for political inclusion at all levels (see case study).

In 1980 an international network of disabled peoples organisations was set up, Disabled People's International (DPI). This works with organisations in 158 countries around the world, exchanging information and experiences and lobbying for change on a more international level.

Despite the growth in the numbers, and influence of, Disabled People's Organisations worldwide, it is still the case that these organisations are largely dominated by urban-based men with physical impairments. People with learning difficulties, leprosy, epilepsy, sensory impairments or mental illness rarely get equal access to cross-impairment groups. Women with these impairments are even more excluded. The exclusion and chronic poverty faced by these groups of people is often even more severe than amongst other disabled people. This situation is beginning to change as more of the most marginalised disabled people are increasingly forming their own groups, or pushing to be included in cross-impairment organisations.

People experiencing several different areas of discrimination are frequently marginalised from all groups. For example, women with mental health problems are often marginalised from the disability movement as well as from the women's movement. In Tanzania, disabled women with HIV/Aids are extremely isolated. Each organisation claims the crosscutting issues not to be their responsibility.

All the actors described above need to be working together in order to reduce chronic poverty amongst disabled people. Full inclusion of disabled people in all areas of society would be beneficial for the whole of society and for development as well as in reducing the isolation and chronic poverty experienced by disabled people themselves.

There follows specific case studies of the situation in Uganda and India. This information was put together with the help of ADD's office in Uganda, ADD India and local disabled people's organisations.

### **Case Study: Chronic Poverty and Disability in Uganda**

Uganda is widely seen as the world leader in terms of political empowerment of disabled people. Constitutional amendments have resulted in disabled people having their own representatives at all levels of government, from the smallest parish level to the national parliament. There are over 47,000 disabled people now elected as politicians. There is also a Minister of Disabled People. Ugandan Sign Language is officially recognised in the constitution (in contrast to the situation in the UK, where sign language is very marginalised). There is not yet a Disability Act but this is currently being worked on. Disability issues generally are high on the agenda for discussion.

Despite these huge advances, disabled people in Uganda are still amongst the very poorest of the poor. Much of the progress has not been translated into real change for disabled people at the grassroots. Many of the disabled people who have recently been elected as politicians have had no previous experience of this work. There is a need for training in order that these councillors are able to effectively represent their constituents. The National Union of Disabled People of Uganda (NUDIPU) is working to train these politicians and to support them in ensuring that their voices are heard within government.

There is a continual need for the disability movement to ensure that these new changes do have a real effect on the lives of disabled people.

The “Universal Primary Education” Act allows for 4 children in each family to get free primary education. Priority officially goes to any children with physical, or sensory impairments in the family. Teachers in mainstream schools are being trained on disability inclusion. All children are to be taught in inclusive mainstream schools, but some disabled children have extra classes with specially trained teachers. In practice however, many parents hide their disabled children away as there is still widespread stigma to having a disabled member of the family and non-disabled children are seen as a better investment for education.

The government is also encouraging universities and vocational training centres to include disabled people. Marginalised groups, including disabled people, are awarded extra points towards entrance qualifications to take account of the disadvantages that they have faced. Support, in terms of interpreters, guides and physical access is provided, in order that disabled people can fully participate. These strategies are all recognised as being short-term measures. The aim is to encourage the whole community to recognise the worth of disabled people and increase awareness of action needed in order to be inclusive.

In Uganda, as in most of the world, there is variation in the level of exclusion faced by people with different impairments. People with mental health problems, especially those with epilepsy or people with learning difficulties tend to be the most severely excluded. Government legislation on prioritising disabled children for school places does not extend to children with learning difficulties or mental health problems. These children are still excluded from education. Even those who come from rich families are frequently not sent to school or given the support they need. This means that as they become adults their poverty increases whatever background they came from.

### **NGOs**

As in other countries, an increasing number of NGOs are recognising the need to include disabled people. This is partly in recognition of the fact that UN targets to reduce chronic poverty are unlikely to be successful unless disabled people are included. It is also partly a result of the wider awareness of the barriers that disabled people face.

There is a growing partnership between government and NGOs. The government often uses NGOs to implement poverty reduction programmes. NGOs may be more efficient in reaching those living in chronic poverty. As part of the government’s Poverty Alleviation Programme, disabled councillors have effectively lobbied to get disabled people included in NGO’s agricultural or credit work.

Many NGOs also devote time to working to influence the government. For example ADD works with Disabled Peoples Organisations to influence the government for wider inclusion of disabled people in their work.

### **Businesses**

There is greater awareness generally of the needs of disabled people and increasing numbers of businesses are becoming more accessible to disabled people. ADD recently held a workshop for representatives of credit providers, NGOs and Disabled People’s Organisations. This was an opportunity for disabled people who had received credit in



the past to talk about their experiences; a chance to influence other credit providers to include disabled people; and to acknowledge that disabled people are as creditworthy as anybody else. The result of this type of lobbying has been an increasing number of credit providers being open to disabled people.

### **Donors**

More donors now insist that those who receive their grants should include disabled people in their work. USAID, for example, state that all recipients of their funds should include disabled people in their work. The extent to which this occurs in practice and to which this includes those living in most severe and chronic poverty is debatable.

### **Churches and Religious Organisations**

Many religious groups are working to address poverty amongst disabled people. For example churches frequently provide support to projects making mobility appliances, in order that they can be sold at low cost.

### **Disabled People's Organisations**

The most ambitious and effective lobbying for disabled people's inclusion has been done by the National Union of Disabled People of Uganda (NUDIPU). This is the umbrella organisation for all Ugandan Disabled Peoples Organisations. At the national level, as well as NUDIPU, there are several impairment specific organisations e.g. the Uganda National Association of the Deaf (UNAD) and the Uganda National Association of the Blind (UNAB). There are also organisations of disabled people at regional, district and local levels. Some groups are impairment specific and some are umbrella organisations.

It is often those disabled people who are least excluded from wider society who dominate in the leadership of Disabled Peoples Organisations. Those disabled people who have been excluded from education and from social interactions all their lives, tend to be amongst the very poorest of disabled people, excluded even from organisations of disabled people. People with mental health problems and with learning difficulties are not generally adequately represented by cross-impairment organisations. Therefore people have been forming their own organisations, for example the Uganda Mental Health Association, the Epilepsy Association and the Association for Parents of People with Learning Difficulties.

Part of the problem for people with mental health problems is often a lack of medical treatment needed to deal with their conditions. For many people with mental health problems, if they get the necessary treatment, then they are able to organise themselves and to campaign for equal rights. However without treatment it is very difficult to organise and to advocate effectively.

The government does not give priority to providing psychiatric drugs. Malarial drugs and those for the wider population are given higher priority. The Minister of Disabled People is working to influence the other ministries to consider the needs of people with different forms of impairments in prioritising government finances.

The new groups of people with mental health problems have been putting increasing pressure on government to recognise their needs. One district authority Mbarara, recently started supplying drugs for people with epilepsy. This was a result of lobbying by the Epilepsy Association with support from the Danish Association for Epilepsy.

Once these drugs are available people with epilepsy often become more confident and effective at organising and working their way out of poverty.

Disabled People's Organisations are increasingly recognising the need to include all disabled people in their work, including those with mental health problems. On the 10th November each year International Mental Health Day is celebrated. This leads to increased public awareness and contributes to reducing the exclusion which people with mental health problems face. On the 3<sup>rd</sup> December each year the International Day of Disabled People is celebrated with a similar effect for people with all forms of impairments.

### **Case Study: Chronic Poverty and Disability in India**

#### **Government**

The Indian Persons with Disability (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 was a landmark in that it was the first major piece of disability legislation based largely on the UN Standard Rules (for the complete Act see [www.disabilityactindia.org](http://www.disabilityactindia.org)). It provided disabled people, in the second largest population in the world, with constitutional recognition. The main provisions of the Act are:

- A. Prevention and early detection of impairment,
- B. Integration of disabled students in mainstream state education,
- C. Reservation of at least 3% of government and public sector vacancies for disabled people – 1% each for persons with visual impairment, hearing impairment and physical impairment,
- D. Identification of jobs which can be held by disabled people,
- E. Job protection for people who have become disabled during service,
- F. Local authorities should, within their economic limits, make adjustments to the physical environment to take account of the access needs of disabled people (e.g. install sound signals at traffic lights, create curb cuts and slopes in pavements, build ramps in public buildings, install Braille systems in lifts).

The Act is currently being revised. The amendment committee published their final report in March 1999 with over 50 amendments. These proposed amendments are now being considered by a government sub-committee. However there has been little sign of progress since the final report was produced. The problems with the Act include:

- Disability is defined in this legislation by a list of only 7 impairments. People with other impairments are technically not eligible for support under this Act. There is, for example, no provision for Sign Language use.
- Many disabled people are not aware of their rights under the Act. In a country with 15 major languages, and low levels of literacy, dissemination of information is a problem.
- There has been lack of political will and excessive bureaucracy in implementing and monitoring the legislation.
- Only 0.14% of disabled people in India have had regular employment since 1960 (Mohan, 1999, cited by Moll, 2001). Therefore the section on preventing dismissal or demotion of disabled people in employment is only relevant to a small minority.
- The Act is not integral to other legislation; e.g. provision for disabled people's education is under the Ministry of Social Justice and Empowerment rather than the

Department of Education and is therefore separate from other legislation on education.

- Each state is obliged to establish a Commission for Disability to promote and monitor implementation of the Act. Of the 29 states, 4 have independent commissions under the Ministry for Social Justice and Empowerment. Most states put disability work as an appendage to another department, reflecting the significance attributed to it. In Karnataka, for example, the person responsible for disability is also the Secretary for Women and Child Welfare.

This Act was obtained through lobbying by disability activists and NGOs. Work was done to educate and mobilise public opinion as well as to influence government officials. Consultation meetings, protest marches and press conferences continue to be held to increase awareness and encourage enforcement. The International Day of the Disabled is a focal point for this work. In areas where there are active organisations of disabled people e.g. Karnataka, Tamil Nadu and Andhra Pradesh, the legislation has been used to help raise awareness of disabled people's rights. Most importantly, the Act helps to put the responsibility on society to make adjustments to include disabled people.

Disabled people's needs however, still remain peripheral to the government's agenda in terms of resource planning and allocation. There is no provision for representation of disabled people in the National Parliament or local government. It has been left to NGOs to promote awareness of the Act, translating it into local languages.

There are several other pieces of legislation and programmes of work, which refer specifically to disabled people. The government also has programmes providing assistance for poor people in general. Individual states then decide whether or not to include disabled people in this work or to consider disability separately.

### **NGOs and donors**

Some NGOs are now moving away from service provision and beginning to focus more on advocacy issues, e.g. improving disabled people's access to statutory entitlements. There is a geographical imbalance in this work. Whereas Community Based Rehabilitation dominates disability work in the south, Institutional Based Rehabilitation is more prevalent in the north. Leonard Cheshire International have noted that while Cheshire homes in the south send children to regular schools; in the north, children are educated within residential homes.

ADD India was established in 1988 and based in Bangalore. Its main activities are around influencing NGOs to include disabled people and supporting disabled people to access their entitlements from the government. It currently works with 29 partner organisations in the south, and is having problems finding suitable partner organisations in the north.

There are several networks of NGOs working with disabled people in Bangalore, Calcutta and Delhi. These are relatively recent bodies formed largely in order to ensure that legislation is implemented. Lobbying by these organisations and by other disability activists have succeeded in getting two questions included in the 2001 National Census. These questions relate to the numbers of disabled people and the types of impairment. Information gathered from this census should help influence policy makers to increase resource allocation in their plans.

In India, as in most countries, there are specialist disability organisations as well as mainstream development organisations claiming to include disabled people in their work. Most NGOs working on disability issues provide specialist services. In the last decade some NGOs have begun focussing on wider issues of poverty alleviation. However disabled people are rarely included in this work, despite being amongst those experiencing the severest forms of chronic poverty.

### **Businesses**

As a result of the Persons with Disability Act, the Confederation of Indian Industry has included disability in its social agenda and is working towards raising awareness in the public sector on issues of employment of disabled people. A few businesses support NGOs in their work among poor people, including disabled people. However most support has been around rehabilitation activities and sheltered employment schemes. The Artificial Limb Manufacturing Company is an example of a parastatal organisation, producing low cost appliances with government subsidies.

There is little acknowledgment amongst the corporate sector of disability rights issues, or of their responsibility to employ disabled people. Generally the preference is for material support where the company logo can be promoted. Support for groups working on disability rights is more limited.

### **Disabled people themselves**

Self-help groups of disabled people are beginning to be recognised in a few parts of the country as another institution to be consulted and represented at local events. This is mainly occurring in the south where NGOs are more engaged in social mobilisation work, e.g. in Andhra Pradesh, Tamil Nadu, Karnataka. In the vast majority of the country, disabled people are still severely isolated and excluded.

A national disability movement is unlikely to be established imminently. The huge size of India is undoubtedly a major factor. The National Association of the Blind is the only national disabled people's organisation with a presence in almost every state. It is primarily involved in vocational training, employment and job placement. DPI India was formed several years ago and now has regional representation in the north, south, east and west.

A strategy for working with rural-based disabled people has recently been agreed. At local level, in Tamil Nadu and Andhra Pradesh, networks of self-help groups are beginning to form federations. Five federations have been established at this time. However, there are few linkages between local and national structures.

### **Summary**

In order to tackle the chronic poverty and exclusion experienced by disabled people in India, action is needed on several fronts. The existing legislation needs to be effectively implemented. The amendments that have been suggested to the Act should be tabled and passed in Parliament. Disability should become an integral part of all national policies. Policies to promote greater participation, representation and involvement of disabled people in decision-making needs to be lobbied for (Wong-Hernandez, 2000). Work needs to be done to influence NGOs, donors, business and the government to include disabled people in all their work. The results of the 2001 census should provide useful statistics to support this lobbying work.

#### **4 Proposal for a research agenda on disability and chronic poverty issues**

As has been described, there is a severe lack of internationally comparable statistics relating to disabled people and chronic poverty. A World Bank report states that, "most nations are now hampered by a paucity of data and information on disability" (Metts, 2000). This is itself a result of the exclusion and chronic poverty faced by disabled people. Most research that does exist has not been undertaken by disabled people themselves, nor has it included disabled people in forming the agenda. Yet, as Metts states, "The real repositories of local knowledge on disability in particular countries are the disabled people that live there, and the most efficient way to tap into their local knowledge is to provide them with mechanisms for making their needs known" (ibid).

Traditional research often involves wealthy non-disabled outsiders questioning people about their lives. This is not a reliable way of getting information where there are big power differences and where questioners are not trusted friends. To get consent is not sufficient, as few people in situations of poverty and exclusion will refuse to be questioned by those with more power and authority (Stubbs, 1999). It is therefore essential that disabled people are fully involved in future research, including setting the agenda.

It is questionable whether it is really a lack of data that is hampering policy makers from including disabled people. However, reliable statistics may help to motivate policy makers to take action. Depending on how the research is carried out, it can also help to change the power relations that exclude disabled people. Disabled and non-disabled researchers need to work together. An investment of time and financial resources is required before many disabled people will be able to effectively conduct research themselves. A lifetime of exclusion cannot be overcome immediately by one researcher.

Some suggestions for areas where research is needed include:

1. Gathering statistics relating to the numbers of disabled people living in chronic poverty. The links can then be presented to policy makers as evidence of the need for policy change.
2. One of the main hurdles, cited by policy makers, to full inclusion is often the financial cost. It is therefore suggested that research is needed on the long-term costs of excluding disabled people – there are large financial and social costs of excluding disabled people from economic activity as well as opportunity costs of exclusion from all mainstream activity.
3. There is also a need to highlight the ways in which disabled people are currently widely excluded even from the work of those development organisations claiming to work on chronic poverty issues. This involves assessing the extent to which disabled people are included in policy making, consultation and implementation of poverty reduction work. The budgetary proportion of development organisation's work that is spent on disabled people could be compared with the proportion of disabled people amongst those living in chronic poverty.
4. In order to improve the situation, it would be useful to gather information on the most effective policies, laws and regulations which can be undertaken in order to include disabled people in poverty reduction work.

It is recommended that a twin track approach is adopted. This means that, in addition to the specific work suggested above, disability issues should be included as a cross

cutting theme in all poverty reduction work and research. Whilst disability is treated solely as a specialist issue, not included in mainstream work, the exclusion and hence the chronic poverty that disabled people face will not be addressed.

**The most important element of any future research is that it is not undertaken as an alternative to tackling the exclusion and chronic poverty faced by disabled people. The research itself should challenge power relations and not just restate issues about which we already know. As Sue Stubbs writes, “don’t get stuck on details that do not make a difference to people’s lives, this is a great academic distraction!” (1999).**

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## Appendix

**UN Standard Rules cover the following areas.** For the full rules see for example annex in DfID's Disability, Poverty and Development issues paper [www.dfid.gov.uk](http://www.dfid.gov.uk)

### 1 Preconditions for equal participation

- Rule 1 – Awareness-raising
- Rule 2 – Medical care
- Rule 3 – Rehabilitation
- Rule 4 – Support services

### 4 Target areas for equal participation

- Rule 5 – Accessibility
- Rule 6 – Education
- Rule 7 – Employment
- Rule 8 – Income maintenance and social security
- Rule 9 – Family life and personal integrity
- Rule 10 – Culture
- Rule 11 – Recreation and sports
- Rule 12 – Religion

### 3 Implementation measures

- Rule 13 – Information and research
- Rule 14 – Policy-making and planning
- Rule 15 – Legislation
- Rule 16 – Economic policies
- Rule 17 – Co-ordination of work
- Rule 18 – Organisations of persons with disabilities
- Rule 19 – Personnel training
- Rule 20 – National monitoring and evaluation of disability programmes in the implementation of the Standard Rules
- Rule 21 – Technical and economic co-operation
- Rule 22 – International co-operation