Disability KAR
Knowledge and Research

Mainstreaming Disability in Development: Country-level research

Rwanda Country Report

Philippa Thomas, Disability Policy Officer
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Copy editing and formatting by Eleanor Stanley and Georgina Kyriacou

Abbreviations and acronyms

AGHR	General Association of Disabled People in Rwanda
CBM	Christian Blind Mission
CBR	Community-based rehabilitation
CESTRAR	Rwandan trade union
CSO	Civil society organisation
DFID	Department for International Development
DPO	Disabled people's organisation
EFA	Education for All
ERJ	Exclusion, rights and justice
ESSP	Education Sector Strategic Plan
FACHR	Federation of Associations and Centres of the Handicapped in Rwanda
FARG	National Assistance Fund for Needy Survivors of Genocide and Massacres in Rwanda
FERHANDIS	Federation Rwandaise Handi Sport
GoR	Government of Rwanda
HSSP	Health Sector Strategic Plan
ICT	Information, communication technology
IE	Inclusive education
JICA	Japanese International Cooperation Agency
KIE	Kigali Institute of Education
KIH	Kigali Institute of Health
MDGs	Millennium Development Goals
MIGEPROF	Ministry of Gender
MINALOC	Ministry of Social Affairs and Local Government
MINECOFIN	Ministry of Economy and Finance
MINEDUC	Ministry of Education, Science, Technology and Scientific Research
MINESANTE	Ministry of Health
MP	Member of Parliament
MTEF	Medium Term Economic Framework
NDRC	National Demobilisation and Re-integration Commission
NGO	Non-governmental organisation
NHRC	National Human Rights Commission
NIS	National Institute of Statistics
NY	National Youth Council
P&O	Prosthetics and orthotics
PDC	Permanent disability certificate
PPA	Participatory Poverty Assessment
PRSP	Poverty reduction strategy plan
RADW	Rwanda Association of Deaf Women
RFR	Rwandan Franc
RNAD	Rwandan National Association of the Deaf
RUB	Rwandan Union of the Blind
SEN	Special educational needs
SHIA	The Swedish Organisations of Disabled Persons International Aid
SWAp	Sector-wide approach
UNICEF	United Nations Children's Fund
UNISE	Ugandan National Institute of Special Education
VSO	Voluntary Services Overseas
WHO	World Health Organization

Contents

Executive summary

Background

This report has been produced by the Disability Policy Officer for the DFID Disability Knowledge and Research (KaR) Programme, as part of a three-country study, taking part in Cambodia, Rwanda and India, to explore how disability relates to DFID's work on achieving the Millennium Development Goals, reducing poverty and addressing social exclusion.

Outline

The first section reviews existing data on the scale and prevalence of disability in Rwanda. Section two outlines the situation of disabled people and examines the relationship between disability and poverty and social exclusion based on existing literature and data, semi-structured interviews with key stakeholders and focus group discussions and home interviews with disabled people. Section three explores how far disability is mainstreamed in Rwanda by reviewing the extent to which existing policy and planning documents on disability are being implemented with particular focus on the key sectors of health and education. The final section provides an overall analysis and recommendations for taking work forward on disability.

Methodology

The research comprised a desk review of documents followed by an 18-day country visit. The key research methods were key informant semi-structured interviews, focus group discussions and home-based interviews with disabled people, field visits to projects and centres and a one-day participatory stakeholder workshop in Kigali. The research was conducted by the Disability Policy Officer and a disabled research assistant from the national disabled people's umbrella organisation, the Federation of Associations and Centres of the Handicapped in Rwanda (FACHR).

Main findings

Disability in Rwanda

According to the 2002 census, just under 5 per cent of the population is disabled, but this is likely to be an underestimate (NIS 2002). Globally, the World Health Organization (WHO) estimates that 10 per cent of any population is disabled and this is the figure used by the Ministry of Health (MINESANTE). There is no accurate data on prevalence of different types of disabilities but, according to the census, physical disabilities are the most common, followed by deafness, mental deficiencies, blindness and trauma. The main causes of disability that informants cited were:

- genocide and war
- poverty (malnutrition, lack of adequate and appropriate medical care)
- ignorance (use of traditional healers, poor care in pregnancy, and so on)
- disease
- accidents
- congenital causes.

In Rwanda, like most developing countries, poverty is not only a cause of disability – it is also a major consequence of disability.

The situation of disabled people
Disabled people are over-represented among the poor and are often among the very poorest. Communities usually identify disabled people as among the most vulnerable groups, along with widows and orphans.

Disabled people share the same problems as the non-disabled poor but they experience poverty more intensely, and attitudinal and structural barriers limit their opportunities to escape poverty.

'Social exclusion' is not a concept that is widely used in Rwanda, but disabled people are both actively and passively excluded in Rwandan society. Rwandans do not value disabled people. Disabled people are seen as objects of charity. They are underestimated and overprotected, and their potential and abilities are not recognised. Disabled children are seen as a source of shame and often hidden away. Name-calling is common. Disabled women find it difficult to get married. Disabled people suffer discrimination in employment.

Disabled family members are sometimes passed over in matters of inheritance. Land and assets are given to others who are deemed to be able to make better use of them, thus leaving the disabled person dependant on family to support them and removing the opportunity for them to lead independent lives. Negative attitudes are particularly strong towards those with severe disabilities, people with intellectual and learning disabilities, blind and deaf people.

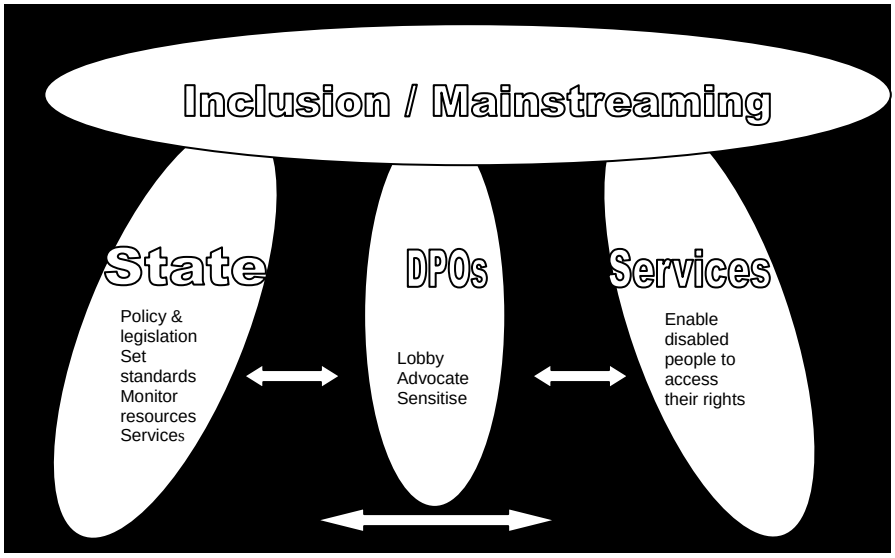
Disabled people are generally excluded from development activities. They are often extremely poor and are continually in 'survival mode', so they literally cannot contribute to development activities, either materially or in terms of their time. They are largely excluded from micro-credit programmes because they lack assets as collateral and are seen as a bad risk. Disabled informants for this study said that they were often not told about development activities in their communities in the first place and when they tried to get involved, they were deliberately excluded.

Mainstreaming disability and development in Rwanda

To develop and ensure the rights of disabled people and equality of opportunity, the three key actors need to work in a coordinated and mutually supportive manner. They are:

- the state
- service providers
- disabled people's organisations (DPOs).

The roles and responsibilities of these actors are illustrated in the diagram on the next page. In Rwanda, all of these key components are broadly in place.



Summary of provision for disabled people (cont. page 7-8)

Legislative and policy framework	
Legislation	*Constitution* Articles 1, 14, 40 *Law Instituting Punishment for Offences of Discrimination and Sectarianism* *Draft Bill on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*
Policy	**Government of Rwanda** *10 Year National Development Plan* includes specific paragraph on disability **MINALOC** *National Policy for the Protection of the Handicapped* (MINALOC) **MIGEPROF** – section on disabled children in *National Policy for Orphans and other Vulnerable Children* **MINEDUC** Education of disabled children included in the *Education Sector Strategic Plan 2004–08* (MINEDUC 2003) **MINESANTE** *Health Sector Strategic Plan 2005–09* (MINESANTE 2005) includes sections on mental health, treatment and prevention of blindness, and rehabilitation for physical disabilities. National plans in place for physical rehabilitation and prevention of blindness

Implementation	
State bodies	
MINALOC	• *National and Provincial Budget for Vulnerable People* (MINALOC. RFR300 million NO IDEA OF EXCHANGE RATE to USD very volatile planned for 2005. Disabled people included within this budget, but in practice very little reaches them. Widows and orphans are prioritised • Established national disability organisation FACHR. Provides office space and some financial support
MINESANTE	• Bureau of Technical Rehabilitation and Prevention of Blindness • Trains physiotherapists at Kigali Institute of Health • Provides limited materials and pays some staff salaries at rehabilitation centres in Kigali University

	Hospital, Butare University Hospital, Kanombe Military Hospital, Gahini Hospital and in seven district hospitals and Ndera Neuro-Psychiatric Hospital
Ministry of Youth and Sport	• Provides office space to FERHANDIS • Supports disabled athletes to participate in national and international sporting competitions
MINEDUC	• Pays teachers' salaries at special schools and some training and materials • Its special needs department coordinates and monitors special schools • Runs one inclusive school: Gahini Secondary School
Local authorities	• Support for disabled people is variable and patchy • Some districts subsidise healthcare and tax exemptions, and provide assistance with housing and school fees
National Assistance Fund for Needy Survivors of Genocide and Massacres in Rwanda (FARG)	• Offers assistance with medical care, education and shelter
National Demobilisation and Re-integration Commission (NDRC)	• Screens and assesses disabled ex-combatants • Provides a lump-sum payment of RFR100,000–500,000 depending on severity of disability • Free medical treatment for disability and free general medical treatment for those with 90–100 per cent disability rating
National Youth Council (NYC)	• Seeking funding to establish Disability Head of Section post and to design a disability-focused programme
Disabled people's organisations	
National Assistance Fund for Needy Survivors of Genocide and Massacres in Rwanda (FACHR)	• Organises and supports national awareness-raising events • Encourages the development of associations of disabled people
General Association of Disabled People in Rwanda (AGHR)	• Encourages development of associations • Carries out awareness raising • Supports education and training
Rwandan Union of the Blind (RUB)	• Runs the Masaka Centre in Kigali (rehabilitation, literacy and numeracy) • Supports associations and awareness raising
Rwandan National Association of the Deaf (RNAD)	• Offers solidarity • Does not carry out any activities due to lack of funds
Federation Rwandaise Handi Sport (FERHANDIS)	• National organisation of disabled sport • Work includes encouraging disabled athletes to participate at international competitions
Services	
Education and training	• seven special schools (operated by faith-based groups)

	• an unknown number of centres offering a range of education and vocational training
Rehabilitation	• **Handicap International** offers support to government rehabilitation centres for prosthetics and orthotics (P&O) and trains P&O technicians and physiotherapists • **CBM** runs a centre in Kigali offering community-based rehabilitation, support for eye care and visiting surgical teams, and training for physiotherapists • **One Love** runs P&O centres in most provinces, and trains training of P&O technicians and physiotherapists • **Gatagara** provides P&O, physiotherapy and surgery

The table below shows an analysis of the strengths and weaknesses of the disability sector, along with current constraints and potential opportunities.

SWOC analysis of the disability sector in Rwanda (cont. page 9)

Strengths	**Weaknesses**
• Strong government recognition of the rights and needs of disabled people (legislation, policies, Disabled MP) • Recognition of disability in national and sectoral plans • Dedicated units in MINEDUC and MINESANTE • Government support (budget for vulnerable groups, FARG, Demobilisation and Reintegration Commission) • Improving attitudes towards disabled people (Para-Olympic bronze medal) • Establishing FACHR • Growing number of associations of disabled people • Political will to implement disability legislation • Good geographical spread of rehabilitation services • Range of dedicated civil society service providers (international and local NGOs, churches)	• Limited and overstretched government resources (no dedicated budget for disabled people) • Patchy and variable government support for disabled people at district level • Lack of coordination and cooperation amongst CSOs in the sector, and with government systems and processes (for example, the Demobilisation and Reintegration Commission has two draft laws on disability) • Lack of data (on, for example, the scale and prevalence of disability, the number of disabled children in and out of school, and mapping of services) • Lack of specific legislation protecting and promoting the rights of disabled people and defining benefits • Weak and unrepresentative DPOs • Lack of access to education, with few improvements since 2000 • Cost barriers to specialist rehabilitation services • Very limited services for mentally handicapped, those with mental health problems and blind people • No services for deaf people and deaf-blind people • Sustainability of services (education and health) questionable • Lack of national standards for care and rehabilitation services
Opportunities	**Constraints**
• Planned surveys, including the household survey, CBM/MINESANTE disability survey, and the UNICEF/DFID/	• Negative attitudes towards disabled people (discrimination and social exclusion)

MINEDUC survey on education for disabled children • National Youth Council • MINALOC's development of social protection policy and system • National Human Rights Commission and Ombudsman • VSO's expanding support to disability • Planned reform of labour law • NDRC Permanent Disability Assessment Certificate screening system	• Dominance of a 'charity' attitude towards disability in Rwanda among disabled and non-disabled people • Legacy of genocide (weak civil society, trauma, social divisions, poverty) • Limited awareness of government policies within local authorities and among disabled people • Public sector reform process (for example, staffing cuts to FARG) • Limited understanding and interest in inclusive education • Unclear lines of responsibility between ministries for different aspects of services and care for disabled people • Limited government resources, with other vulnerable groups prioritised over disabled people • General failure of development programmes and initiatives to reach the very poorest and disabled people in particular (for example, HIMO, Ubedehe or micro-credit schemes)

In its PRSP, the Government of Rwanda commits itself to:

> "securing for all its citizens a full range of social, economic and political rights, and to working with its people to reduce poverty and exclusion."
> (PRSP 2002 p 6)

However, progress towards reducing poverty and exclusion in Rwanda will be constrained unless specific measures are taken to dismantle the particular barriers that disabled people face that trap them in a vicious cycle of poverty and unnecessary dependency.

Recommendations

Enact specific disability legislation
Specific legislation enshrining and promoting the rights of disabled people is critical. It should define clear roles and responsibilities for government and civil society. It should also establish accessibility criteria for new buildings, and designate certain benefits and entitlements. Separate legislation for disabled ex-combatants is not desirable: their particular needs can be recognised with one single disability law covering all disabled Rwandans.

Strengthen coordination and disabled people's organisations
The effectiveness of the disability sector is being undermined by a lack of coordination within government ministries and with, and between, civil society actors. Such coordination could be led by MINALOC, or preferably by FACHR. The Disability Action Council in Cambodia could provide a potential model. FACHR will need considerable organisational development and capacity building, as well as increased support, if it is to fulfil such a role. If FACHR establishes district level representation as it hopes to do, it could also facilitate the distribution of any future designated budget allocation for disability.

Rwandan DPOs are currently weak and not representative. They need to be strengthened so that they can effectively advocate for the rights of disabled people with government, donors and society as a whole. International NGOs currently involved in the sector, such as Handicap International, CBM and VSO, should consider how they can give greater support to the development of Rwandan DPOs alongside continued support to service provision.

The Government of Rwanda also needs to clarify ministerial responsibilities for disability. There is insufficient government overseeing of centres and special schools. This is partly because of lack of information about services (see the following recommendation). Nevertheless long-established facilities seem unclear about which ministry they should link with. There is a real risk that vulnerable disabled people – particularly disabled children and people with mental handicaps – could fail to be adequately protected because of the lack of clear ministerial supervision and monitoring of special schools and centres.

Improve data collection and information on disability
Government and NGO planning for the sector is being hampered by the lack of data and information. There is an urgent need to harmonise the various surveys planned (the national household survey, the MINEDUC/UNICEF/DFID survey on disabled children in and out of school, MINESANTE/CBM survey on disabled people). A single classification system for disability needs to be established and used by all in future data collection from the national census to small-scale surveys by NGOs and DPOs. The Cambodian classification system could be a model (see Annexe 6). A comprehensive mapping of existing services is also a priority.

Establish a comprehensive social protection policy with a designated budget for disability and specified benefits for disabled people, based on need
MINALOC is eager to harmonise existing social protection mechanisms within a comprehensive single social protection framework. Disability needs to be specifically included within such a framework, with a designated budget allocation, otherwise other groups are likely to be prioritised over disabled people, as currently happens with the MINALOC budget for vulnerable groups.

Disability benefits and entitlements should be allocated on the basis of need. Preferential treatment for disabled genocide survivors and ex-combatants should be discontinued. The NDRC's Permanent Disability Certificate screening and assessment system could form the basis of a national disability assessment system.

Reduce the cost barriers and improve the financial sustainability of rehabilitation services
Cost is the major barrier preventing disabled people from accessing specialist rehabilitation services. Over the next few years, the Government of Rwanda plans to expand the Mutuelle Funds health insurance system. In the future, all Mutuelle systems should cover all, or at least part of, the costs of rehabilitation and eye-care services. Given that disabled people generally require more health services than non-disabled people, when it comes to subsidising membership of Mutuelle systems, priority should be given to those disabled people most in need.

In addition, monies collected from user fees at government rehabilitation centres could be ring fenced and retained for use for rehabilitation. This would significantly improve the financial sustainability of such services.

Establish a national policy on education for disabled children with a strong focus on inclusive education
The MINEDUC/DFID/UNICEF planned survey on disabled children in and out of school is very welcome. MINEDUC needs to use the results to develop a comprehensive policy on education for disabled children. Inclusive education is strongly recommended as the central focus of such a policy. Efforts need to be directed at building the knowledge and capacity of mainstream teachers to accommodate and meet the needs of disabled children in regular schools. Meanwhile, special schools need to work towards developing as resource centres.

Inclusive education should be seen as a key way to achieve education for all and improve quality in Rwandan schools. Schools in the inclusive education programmes in Laos and Cambodia outperform other schools, with higher enrolment rates and lower repetition and drop-out rates.

Improve access to information and services on HIV/AIDS for disabled people
Disabled informants for this study consistently raised the lack of access to information and services on HIV/AIDS – particularly for blind and deaf people. Government and civil society bodies working in the field of HIV/AIDS need to recognise that disabled people are particularly vulnerable, and take steps to ensure that they specifically include and target them in their awareness-raising and information activities.

Continue to support and develop sensitisation campaigns on the rights and abilities of disabled people
Sensitisation activities need to be supported and developed because, as the Ombudsman Adjoint Bernard Ndashimye put it, “The legal system can provide rights but implementation depends on the mind” (personal communication 2005).

Development activities and programmes must seek to ensure that they actively include disabled people and do not unwittingly discriminate against them
It cannot be assumed that disabled people will benefit from development activities in the same way as non-disabled people. If development activities are really to reach the poorest, then special efforts need to be made to remove the barriers (attitudinal, environmental and institutional) that prevent disabled people from participating.

Conclusion

Rwanda has made extraordinary progress since the genocide, and the country is well placed to make similar progress with regard to disability. All the key components are broadly in place, and the government should be congratulated for its recognition of the needs of disabled Rwandans. All stakeholders in the sector need to work together to support each other and the government, to build on the firm foundation that already exists, and to ensure that commitments on paper are fulfilled by concrete actions on the ground.

The process of conducting this research has raised awareness of disability issues, as well as facilitating the first ever stakeholder workshop on disability in Rwanda, funded by the Disability KaR programme and organised by VSO. It is hoped that this report will also be of use to the government, donors, international and local NGOs and DPOs, to take forward work on disability.

1. Introduction

Background

This report has been produced by the Disability Policy Officer for the Policy Project of the Disability Knowledge and Research (KaR) programme, funded by the UK Department for International Development (DFID).

The second phase of the DFID Disability Knowledge and Research (KaR) programme began in September 2003, managed by a consortium of the Overseas Development Group at the University of East Anglia and Healthlink Worldwide. The Disability KaR has developed a focus on mainstreaming disability in development.

The programme comprises several components, including:

- research on disability mainstreaming the links between disability and poverty
- developing training courses on disability and development
- holding regional roundtables on disability and development themes
- the Disability Policy Project, which has involved the placement of a technical adviser (the Disability Policy Officer) on disability issues within DFID's Policy Division.

One of the Disability Policy Officer's first activities was to complete a report mapping what DFID is currently doing to support disability worldwide. The main findings of the report were as follows:

- DFID has not mainstreamed disability, but there is a solid bedrock of disability-specific activities being carried out, largely via non-governmental and civil society organisations.
- DFID's work on disability is largely hidden, and often its staff and country offices are unaware of disability-focused activities that non-governmental and civil society organisations are carrying out.
- While DFID staff broadly recognise the links between poverty and disability, they do not necessarily see disability as an essential part of their work on poverty reduction and the achievement of the Millennium Development Goals.
- DFID staff need more information on disability – in particular, practical tools and examples of best practice – to enable them to implement the twin-track approach outlined in DFID issues paper *Disability, Poverty and Development* (DFID 2000).

It was decided to follow up this mapping by conducting three studies on disability mainstreaming in countries in which DFID works. The aims of these studies are:

- to explore how disability relates to DFID's work on reducing poverty and social exclusion and to achieving the Millennium Development Goals
- to map disability-focused activities in each country
- to identify examples of best practice
- to explore the opportunities and constraints for raising the profile of disability within each DFID programme
- to identify potential partners for DFID to take forward work on disability.

Specific terms of reference are agreed for each country. This Rwanda report is the second of the three studies, with the other two being conducted in Cambodia and India. A final report synthesising the findings from the country research will be produced.

The Disability Policy Officer works closely with the Exclusion, Rights and Justice (ERJ) team within DFID Policy Division. In conducting this research, the Disability Policy Officer also worked closely with the DFID Rwanda Social Development Adviser.

Methodology

The Disability Policy Officer and a disabled assistant researcher from the Federation of Associations and Centres of Disabled People in Rwanda conducted the research for this study. The research comprised a desk review of literature and an 18-day field visit to Rwanda during January 2005.

The primary research method involved carrying out key informant interviews. Field visits were conducted to:

- Gatagara Centre (Gitarama)
- One Love Project, Kigali
- Ndera Mental Health Centre (Kigali Ngali).

Focus group discussions were held with 27 disabled people in Gisenyi and 20 disabled people in Ruhengeri. Four individual interviews were held with disabled people in Kigali Ngali.

Constraints

There were three main constraints in carrying out this research:

- Time was a serious constraint. It was not possible to meet with all relevant stakeholders.
- The disabled people who participated in interviews, focus group discussions and field visits cannot be said to be representative of the majority of disabled people in Rwanda. This is because they were all members of associations of disabled people. However, where possible, efforts were made to ensure that the participants were of different ages, sexes and had a range of impairments.
- The Disability Policy Officer was new to Rwanda, and language difficulties were a constraint.

Outline

The following section provides a summary of disability in Rwanda, examining the existing data on disability rates, prevalence and causes. Section 3 outlines the situation of disabled people, and examines the relationships between disability, poverty and social exclusion. It is based on existing literature and data, semi-structured interviews with key stakeholders and focus group discussions, and home interviews with disabled people. Section 4 explores how far disability is mainstreamed in Rwanda, by reviewing the extent to which existing policy and planning documents on disability are being implemented. It particularly focuses on the key sectors of health and education. The final section provides an overall analysis and recommendations for taking forward work on disability.

Acknowledgements

We would like to thank all those who provided information for this study and who participated in interviews – in particular, all the DFID staff in Rwanda, and Judy

Walker, Social Development Adviser, for their support and cooperation. We would also like to thank VSO Rwanda for offering to organise a participatory stakeholder workshop, and for doing the job so well. Finally special thanks are given Bernard Bagweneza, the research assistant, and to all the disabled people who took part in interviews and who generously shared details of their lives, and often very painful memories.

Little boy at Gatagara Centre

2. Disability in Rwanda

Defining disability

There is no universally agreed definition of disability. Historically, disability has been seen primarily as a medical condition – a problem located within the individual. Since then, this medical, or individual, model has been challenged by disability activists who reconceptualised disability as primarily a social phenomenon. This social model of disability draws a clear distinction between 'impairments' and disability. It argues that it is society that disables people who have impairment, through its failure to recognise and accommodate difference, and through the attitudinal, environmental and institutional barriers that it erects against people with impairments. Disability thus arises from a complex interaction between health conditions and the context where they exist.

This social understanding of disability has gained widespread acceptance, and is reflected in UN World Programme of Action for Disabled Persons and the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, in the WHO International Classification of Functioning Disability and Health (ICF), and by the World Bank, DFID and others.

Understanding of disability in Rwanda

The draft Law on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities defines disabled people as:

> "Persons who were born without physical, mental or psychological ability like that of others or who were deprived of it due to illness, accident, war or old age."
> (Draft Disability Law, Article 1, unpublished)

This definition is widely understood, and informants for this study generally defined disability in a similar way. However, there is no agreed classification system. Such a system is needed so that all data gathered, whether by government or civil society organisations (CSOs), can be consistent and comparable.

One example of such a system is that of Cambodia. The Cambodian classification system was agreed by all stakeholders, and classifies types of disability according to the difficulties people face – for example, in seeing, hearing, moving, speaking, learning or psychologically. The system is easy to use and ideal for use in the community enabling local people to describe the functional problems of disabled people in their communities. It is not necessary to have medical training to use the system.[1]

Scale and prevalence of disability in Rwanda

In the 2002 national census (NIS 2002), less than 5 per cent of the population declared having any major disability. However, this figure is probably an underestimate. This is because the stigma attached to disability in Rwandan society is likely to have limited some households from declaring their members as having a

[1] See Annex 6 for Cambodian classification system

disability. In addition, the categories of disability were quite narrow. According to the Census categories, the most common types of disability were 'upper limb', 'lower limb', 'others', 'deaf/dumb', 'mental deficiency', 'blind', and 'trauma' (NIS 2002).

The World Health Organization (WHO) estimates that approximately 10 per cent of any population, worldwide, is disabled. This figure is used in the Ministry of Health's *National Plan for the Rehabilitation of Disability in Rwanda* (MINESANTE 2002), which estimates that 4.8 per cent of the disabled population have moderate or severe disability.

The lack of accurate data on scale and prevalence of disability is a common problem around the world. Disability rates depend on the definitions and categories used. Disability is a relative term, with some impairments being more or less disabling depending on the environments in which they occur (Elwan 1999). The Christian Blind Mission (CBM) is working with MINESANTE to plan a disability survey in Rwanda later in 2005. In the meantime, a snapshot of the kinds of disabilities in Rwanda can be glimpsed from the records of the oldest and best known rehabilitation centre, Gatagara, in Gitarama Province. The table below shows the physical disabilities and conditions of the centre's clients in 2003.

Records of conditions and disabilities of patients at Gatagara Centre 2003
(cont. p 17)

A: Conditions of the central nervous system	**Number**
Cerebral palsy	83
Little's syndrome	7
Psycho-motor retardations	15
Hemiplegia	63
Paraplegia	19
Tetraplegia	5
Microcephalus	3
Dwarfism	4
Hydrocephalus	9
Down's syndrome	4
Spasms	5
Sub-total	217 (26%)
B: Conditions resulting from infections diseases	**Number**
Polioarthritis	32
Osteomylities	22
Spinal TB	4
Sub-total	58 (7%)
C: Conditions of peripheral nerves	**Number**
Polio	97
Ebb's palsy	5
Sciatica	9
Periphoma	1
Radial nerve paralysis	4
Facial paralysis	4
Sub-total	120 (15%)

D: Orthopaedic conditions	Number
Foot deformities and functional problems	135
Knee deformities and functional problems	
Hip problems	78
Bouttonier's deformity (hand)	9
Contractures of muscles	3
Limb-length discrepancies	4
Amputations	25
Burn injuries	76
Scoliosis	3
Others (Pathe's disease, Lobstein's disease, agenesis)	3 29
Sub-total	375 (46%)
E: Rheumatism conditions	**Number**
All major types of rheumatism	23 (3%)
F: Hereditary conditions	**Number**
Myopathy	8 (1%)
G: Other conditions of unknown origin	**Number**
Muscle weakness	6
Hip pain	3
Lipoma	3
Keloids	4
Frozen shoulder	2
Eye problems	1
Thigh pain	1
Chest deformity	1
Spinal disc degeneration	1
Sub-total	22 (3%)
Total	**823 (100%)**

Causes of disability

Accurate data on the causes of disability were not available. However, informants for this research identified the following:

- genocide and war
- poverty (including through malnutrition and lack of access to medical care)
- ignorance (for example, use of traditional practices, poor care in pregnancy)
- disease
- accidents
- congenital

Disability and the genocide in Rwanda

The perpetrators of the 1994 genocide did not specifically target disabled people in the way that took place under the Nazi regime and, to a lesser degree, by the Khmer Rouge in Cambodia. Nevertheless, the genocide and disability are intertwined:

> "It appears that large numbers in Rwanda became disabled during attempts to terrorize them or their relatives and subsequent attempts to kill them were botched… In many cases, though, attempts at killing

were not botched and where mobility was impeded death was often the consequence. In many cases individuals escaped death, but did not escape disability either through malnutrition or Post-Traumatic Stress Disorder."
(Blaser 2002, p 58)

The National Assistance Fund for Needy Survivors of Genocide and Massacres in Rwanda (FARG) estimates that 300,000 survivors of the genocide were disabled, and that approximately 26,000 were missing one or more limbs. Mutabazi (1998) notes that there was a large-scale slaughter of deaf people, and that Hutu soldiers and death squads killed almost all of the 750 mentally handicapped patients in Rwanda's psychiatric hospital.

Many were disabled by the conflict. For some, this was the direct result of the injuries they received through mines, bombs and bullets. For others it took place indirectly, through the disruption to vaccination programmes and the collapse of heath system which led to their not being able to get appropriate treatment. The trauma experienced by genocide survivors is only beginning to be recognised, and there are no comprehensive studies on its effect on the mental health of the population.

The conflict also impacted heavily on services and associations of disabled people were also heavily impacted. Of the 15 members of the committee of the General Association of Disabled People (AGHR) in Rwanda, only three survived (personal communication, 2004). Centres for disabled people were ransacked. After the genocide, outside aid groups were hampered by threats of danger and challenges to their neutrality, and many chose to leave (Blaser 2002).

The genocide and conflict seems to have had one unexpected positive result. The large increase in the disabled population has meant that disability has become far more visible. The Government's commitment to supporting genocide survivors has seen specific commitments in legislation and policy towards disabled people. Furthermore, in Rwandan society in general, traditional and negative attitudes towards disabled people – particularly those with physical disabilities – have been challenged as more individual have encountered disability in their own families and communities.

Clearly significant numbers of people became disabled because of war and the genocide of 1994, but the data from the Gatagara Centre suggests that in fact this is not the major cause of disability. As with most developing countries, much of the disability seen in Rwanda is preventable. Poverty is not only a cause of disability – it is also a major consequence of disability.

3. Disability, poverty and social exclusion in Rwanda

> "Rwandans see people with disabilities as meaningless."
> Disabled man, interview, Gisenyi

Conceptual understandings

An holistic conceptualisation of poverty that encompasses concepts such as vulnerability, lack of voice and access to natural resources and services, as well as income deprivation, is widely understood and used by government and development actors in Rwanda. However the concept of social exclusion is not so widely recognised and used. DFID's working definition of exclusion is:

> "the experience of certain groups who suffer discrimination on the basis of their social identity and are excluded from economic, social or political opportunities as a result. This discrimination may operate at the level of state policy, institutional bias, social practices, or historic neglect."

Social exclusion complements holistic understandings of poverty, by adding a dimension of causality – namely, that someone or something is doing the excluding. Social exclusion is a particularly useful concept for understanding the dynamics of disability and poverty. The concept chimes with the social model of disability, which emphasises the institutional, attitudinal and environmental barriers in a society that disables people with impairments.

All the informants for this study recognised that disabled people were among the poorest of the poor in Rwanda. Most saw disability as primarily a poverty issue, though a minority also identified it as a rights issue. No one identified disability as predominately a medical issue. Save the Children noted that communities usually identify orphans and disabled children as being the most vulnerable.

There is no national data on the nature and depth of poverty experienced by disabled people compared to non-disabled people. As a result, evidence for this section is largely qualitative, drawn from interviews for this study, two focus-group discussions with disabled people in Gisenyi and Ruhengeri, and home interviews with individual disabled people in Kigali Ngali. The aim is provide a snapshot of the lives and situation of disabled people in Rwanda, and to capture some of their voices and stories.

The situation of disabled people in Rwanda

According to the PRSP, 60 per cent of Rwandans live below the poverty line of US$1 a day. In rural areas, the figure is higher. The PRSP identified six kinds of households, as detailed in the table below (cont. p 20):

Category of household	Characteristic
Umutindi nyakujya ('those in abject poverty')	Those who need to beg to survive, have no land or livestock, lack shelter, adequate clothing and food. They fall sick often, have no access to medical care, their children are malnourished, and they cannot afford to send them to school.
Umutindi ('the very poor')	The main difference between this category and the one above is that people in this group are physically

	capable of working on land owned by others, although they themselves have either no land or very small landholdings, and no livestock.
Umukene ('the poor')	These households have some land and housing. They live on their own labour and produce, and although they have no savings, they can eat, even if the food is not very nutritious. However, they do not have a surplus to sell. Their children do not always go to school, and they often have no access to health care.
Umukene wifashije ('the resourceful poor')	This group shares many of the characteristics of 'the poor', above, but in addition, they have small ruminants and their children go to primary school.
Umukungu ('the food rich')	People in this group have larger landholdings with fertile soil and enough to eat. They have livestock, often have paid jobs, and can access health care.
Umukire ('the money rich')	Members of this group have land, livestock and often salaried jobs. They have good housing, often own a vehicle, and have enough money to lend and get credit from the bank. Many migrate to urban areas.

Source: Adapted from PPA , quoted in the NPRS 2002, p 15, MINECOFIN

Households headed by widows, children, the elderly and disabled people are likely to be poor. Women and girls usually have the responsibility of collecting water, and sources of potable water are often some distance away – on average 703m, but in Kibungo, Kigali Ngali, Umutara and Butare, often much further. The adult literacy rate is low, at 52 per cent (NPRS 2002).

Poverty and disability

Disabled people typically share the profile of other poor people in Rwanda. However, because of their disabilities they are more vulnerable to poverty, their experience of poverty is more intense, and their opportunities to escape from poverty are more limited.

Case study: Marie
Marie is 41 years old. She has two children: a boy aged 12 and a girl aged 10. Her husband was killed in the genocide. Marie had polio as a child. She has orthoses on both legs and uses crutches to get around, which a local priest helped her to get, but they are now very old and desperately need repairing. She has a very small plot of land (less than 900 sq m), which she is now unable to cultivate because of her broken orthoses. The nearest source of water is 4 km away. If her children cannot fetch water, she has to pay RFR100 for someone to do it for her.

Marie and her family do not have enough food for most of the year. She subsists largely on gifts of money from friends, which she uses to do some small trading. In her cell[2], everyone except her received a goat through the Ubedehe Programme, an EC funded community development programme. She was told that as she had no land and was disabled, she couldn't care for the goat. She cannot access micro-credit as she has no collateral and is considered a bad risk.

[2] A cell is the smallest administrative unit in Rwanda, approximately 200 households

Marie is trapped in a vicious cycle of poverty and dependence. Simple repairs to her appliances would liberate her and enable her to lead an independent life again. She says, “My disability troubles me everyday. I cannot cultivate, my appliances need repairing, I cannot move, I am dependent.”

Interview, Kigali Ngali

Poverty is recognised to be a major cause of disability in the developing world, and most disability is preventable or treatable (DFID 2000, Elwan 1999). Because poor people lack access to basic health care, simple infections, illnesses and injuries go untreated or are mistreated, often resulting in permanent disability. Grinding poverty often brings psycho-social mental health problems, such as depression and anxiety, which can be very disabling and to which women are particularly vulnerable. This is in addition to the ongoing trauma that many of the population experience because of the genocide. Food insecurity is a major problem. Child malnutrition is estimated at 6.7 per cent for wasting, and 47 per cent of children are stunted (NPRS 2002). Malnourishment is a major cause of developmental delay and long-term intellectual disability.

In addition to causing disability, poverty is a major consequence of disability. Informants noted that they became poorer after they were disabled. Disabled people generally are ill more often than non-disabled people and clearly disability impacts heavily on an individual’s ability to earn a living.

Attitudes towards disability

All the informants reported that a negative attitude towards disabled people among Rwandan society. Disability is a source of shame in a family. Disabled people are underestimated, being seen as useless, meaningless, recipients of charity who need to be cared for because they cannot do things for themselves. Such attitudes consign disabled people to the role of passive victim. In such a climate of negativity, disabled people themselves begin to doubt their abilities and potential.

> “When you are a disabled person, you live with your disability, you have to accept your disability and wait for what God will do for you.”
> Sixty-year-old disabled woman, interview, Kigali Ngali

Name-calling is common. Often disabled people are commonly addressed by their type of disability rather than their real name. In Kinyarwanda, the personal prefix used for people is often replaced by that for a small, inanimate object, so *umu-ntu* (‘person’) becomes *iki-muga* – ‘a disabled person’ or, literally, ‘a worthless, broken piece of pot’ (VSO 2001).

Disabled women find it difficult to get married. Informants noted that if disabled women do marry, there are often problems with the husband’s family and the wife is often maltreated by their husband. There is also a belief that disabled women are sterile or that if they do have a child, that the child will be disabled. However, in Rwanda, women who become disabled or who give birth to disabled children are seldom abandoned by their husbands, unlike in neighbouring Uganda.

Disabled children are seen as a source of shame for the family. They are often hidden and may receive less food than their non-disabled siblings. Infanticide of disabled children is likely to occur, but it is impossible to quantify the scale of the

practice. Community-based workers report that it is common to find severely disabled children, and particularly those with mental handicaps and cerebral palsy, living in appalling conditions. They are often without clothes, unwashed, and sometimes in cages. However the cause is ignorance rather than deliberate maltreatment. Parents are unlikely to have ever seen another child with a similar condition, and they do not know how to help their child to learn to feed, dress and wash.

Attitudes to disabled people vary according to their type of disability. Physical disability is the most accepted form of disability, and amputees seem to suffer less from negative attitudes than other physically disabled people. This is probably because of the large increase in such disabilities through the genocide and war. Blind people are seen as particularly helpless. At home they are not encouraged to do anything – not even simple household tasks.

Deaf people are particularly isolated. Blindness cuts an individual off from their surroundings, but deafness cuts them off from other people. There is no national sign language, though signing does exist and some people learn to lip read. Nevertheless, most deaf people suffer extreme isolation and are often unable to communicate even the most basic things to their families. There are no services or help available for the deaf-blind, and one can only conjecture on the extreme difficulty of their situation. In Rwanda, as in most societies, people with mental handicaps and mental health problems suffer from more discrimination than people with other types of disability.

> "My father hates me. My mother is dead. My father doesn't give me anything to eat. I have a friend. She [the founder of the centre] is my friend."
> Mentally handicapped girl, interview, Gisenyi

Sexual violence and abuse is a significant problem in Rwanda. Disabled women and girls are particularly vulnerable – especially those who are blind, deaf or mentally handicapped, as they are unlikely to be able to communicate what has been done to them or identify their abuser. During the research, informants cited a number of individual examples of rape and sexual abuse within communities, and in special schools and centres for disabled people, often resulting in pregnancies. If an abuser is identified within a facility, they are dismissed. One centre providing day care for mentally handicapped children contacted the police over the rape of one child in the community. The authorities were very supportive and the individual was arrested, but escaped before a trial could take place.

Changing attitudes towards disability: disabled sport (cont. p 23)
Rwanda won its first-ever Olympic medal, a bronze in the 800m in the Para-Olympics in Athens 2004. This sporting achievement received widespread media coverage, but this individual success was built on a growing movement of disabled sportsmen.

The Federation Rwandaise Handi Sport (FERHANDIS) was established in 2001, and nationally approximately 120 disabled sportsmen are involved in volleyball, athletics, swimming, table tennis, cycling and others. The national disabled volleyball team has competed in international disabled tournaments in Germany and Canada. Disabled cyclists have competed against non-disabled peers in races in Kigali.

Sport helps to integrate disabled people in society, builds their self-confidence, and brings well needed income to some of the disabled athletes as well as the

opportunity to travel. The Para-Olympic medal 'succeeded in showing our government and people that people with disabilities can do something for our country' (Dominque Bizimana, President, FERHANDIS.

(Photo: New Times)

Social exclusion

The generally negative attitudes to disability, and stigma attached to it, result in social exclusion for disabled Rwandans. However, the degree of exclusion appears to be largely dependent on the severity and type of disability. Those with severe disabilities, such as blindness, deafness, mental handicap and mental illness, are the most excluded.

Disabled women are more excluded than disabled men. Most of the female disabled informants were not married. Disabled men agreed that it was more difficult for disabled women to marry than a disabled man. If a disabled man had means, then he was likely to be able to find a wife. Similarly, disabled men were more likely to participate in community events, and their voices more likely to be heard and their views listened to in community meetings than disabled women. Disabled women complained that they were not listened to, and often not informed about community activities and development projects.

Disabled people tend to be excluded from development activities. They experience extreme difficulties in accessing micro-credit because they are often very poor and lack assets to guarantee loans. They are also seen as a bad risk.

None of the disabled people who participated in this study had been involved in the HIMO programme or other cash or food-for-work programmes, nor did they know of any disabled person who had. Some had applied but been turned away because of their disability. These programmes involve often hard manual labour, which clearly makes it difficult for many disabled people to participate. Nevertheless there are jobs that they can do, such as time-keeping or supervision. Similar programmes in Afghanistan specifically allocate these jobs for disabled people, but this is not the case in Rwanda. The disabled informants claimed that they were often not informed about development activities, and that others were usually prioritised for participation and receipt of benefits over them.

> *"I am handicapped for nine years, People call me names. I am refused a job."*
> Cyrille, amputee, interview, Gisenyi

There is growing awareness that development initiatives tend not to be very good at reaching the very and chronically poor (CPRC 2004). A recent report noted that in Rwanda, many development activities 'reach only a very small minority of the needy' (Bangwanabusa 2004, p 47). An evaluation of the Ubedehe programme also commented that 'the poorest are surely not the first ones to gain from this project, contrary to its rhetoric' (Uvin and Nyirankundabera 2003). Disabled people are typically among the poorest but are often further excluded from development initiatives because of their disability.

Religion plays an important part in the lives of most Rwandans, with churches and mosques being a centre for social activities. Christian organisations provide services for disabled people, and support and run most of the special schools and centres for disabled people. However outside of these specialised facilities, disabled people, including regular churchgoers, appear to get very little or no support from their local church

> "When I was 15 years old, I thought I would become a nun. I went to the nuns to ask if I had a vocation. They told me that this is not a shelter for those who can't get a husband."
> Amelie, young woman with polio, interview, Gisenyi

Nearly all the informants for this study said that disabled people suffer discrimination when it comes to formal employment. Unemployment is a serious problem in Rwanda. Many of the disabled people who took part in the focus group discussions were educated but complained that even if they were equally or better qualified for a job, non-disabled applicants were preferred. Out of the 47 disabled people in the two focus group discussions, only 14 were in paid employment. Five worked in the public sector. The rest in the private sector, but were mainly employed by NGOs offering services to disabled people.

The Rwandan trade union CESTRAR confirmed the discrimination faced by disabled people in employment, as did informants working for MINALOC and MINEDUC and representatives from disabled people's associations. CESTRAR was also concerned that the disabled public sector employees might be disproportionately affected by the current rationalisation process. Disabled public sector employees are more likely to working in lower grade positions and have less academic achievements making them more vulnerable to being laid off.

However, disabled people in Rwanda do not appear to suffer from political exclusion. All the disabled focus group participants who were eligible had voted in the various elections and referendum on the constitution in 2003. Although the government has not introduced tactile ballots, it has given special consideration to the needs of disabled people.

The National Electoral Commission described efforts to ensure that polling stations were as accessible as they could be, given the hilly terrain of Rwanda. Staff helped disabled people, and blind people and others needing special assistance were allowed to nominate someone to accompany them and help them cast their vote at the polling station. The system appears to have worked generally well, although blind people said that they could not confirm that their helper had actually voted according to their wishes.

Disability and livelihood

In Rwanda, approximately 90 per cent of the population is involved in agricultural activities. A disability clearly impacts on an individual's ability to do such work. Most disabled people lack access to education, and illiteracy among disabled Rwandans is higher than in the general population. As has been noted, even educated disabled people find it particularly difficult to get paid employment.

> "For me, I don't know how to write. I fees sadness when I look at other people. It comes from my heart. How do I get a job and do other things?"
> Young man with both hands amputated, interview, Gisenyi

Disability severely limits the livelihood options for individuals. Rwandan society puts great importance on contributing to the household economy, and status is conferred on those who contribute the most. Disabled people's self-esteem is reduced because they are not able to contribute as others do, and consequently their status is also negatively impacted.

Disabled people often do not inherit land, livestock or possessions in the same way as non-disabled family members. Inheritance is often passed onto to those who are deemed to be able to make better use of the assets. This is an economically pragmatic decision in families, but it often renders the disabled person entirely dependent on their family to support them, and removes opportunities for them to live independent and fulfilled lives.

Case study: Odetta
Odetta is 60 years old. She had a serious car accident in 1986 and received poor medical treatment, resulting in permanent disability. Her one leg is useless, she is in constant pain, and her leg injury has never properly healed, so she is often afflicted with infections that incapacitate her. She gets about slowly with two old wooden crutches.

Three of Odetta's orphaned grandchildren live with her in their small two-room house. The house is old and the roof needs repairing. Odetta's husband died in 1988 and two of her children died in the war. Her surviving children took over her land, with her consent, because she couldn't manage it. She now relies on them heavily but they cannot provide enough support for Odetta and the three grandchildren.

Odetta is a skilled basket weaver, but her mobility problems prevent her from gathering the raw materials she needs. She is trying to improve her situation by learning to read and write in an adult literacy programme. Cost and distance are the main barriers preventing her from accessing better treatment for her leg, and improved assistive devices, which could transform her mobility and enable her to fully utilise her skills as a basket maker. At the moment, however, she is trapped and often has to resort to begging in the market.

Interview, Kigali Ngali

Where disabled people do have assets, their disability often limits their capacity to utilise them fully. Access to micro-credit is particularly limited for disabled people.

Many disabled people earn a very meagre livelihood by engaging in small trading. Others rely on gifts from friends and family, and many have to resort to begging.

Case study: Claude
Claude is 49. He is married with four children under the age of eight. He became disabled after contracting polio when he was 14. His mobility is restricted, but he can walk without crutches.

Claude's parents and brothers and sisters and his wife's parents and brothers and sisters were killed in the genocide. He now lives with his family in a house built by Oxfam. Access to water is a big problem. The nearest source is poor, and is 1 km away, up a very steep hill. Claude has 1 hectare of land, which he inherited from his parents, but it is 10 km away from his home, and his disability means it is difficult for him to cultivate it. His wife helps, and if he has money he hires a worker, but he is not getting full benefit from this land. He has thought about selling it, but land closer to his house is more expensive, so he could not afford to buy a hectare. He has thought about using his land as collateral for a loan, but he is not sure. He has tried to join local micro-credit initiatives but he has not always been able to keep up the weekly repayments.

Interview, Kigali Ngali

In Rwanda, disabled people have to struggle against the difficulties of their impairments as well as the negative attitudes of the society, which largely sees them as worthless and unable to contribute to their families. This can become a self-fulfilling prophecy, as others receive preferential treatment in terms of inheritance, so that their physical assets are very limited. Most disabled people are poorly educated or illiterate. They are discriminated when it comes to employment and are excluded from development activities. Many become trapped in a cycle of poverty with few opportunities to escape.

4 Mainstreaming disability in development in Rwanda

> "There is great political will for people with disabilities in Rwanda."
> Bernard Ndashimye, Ombudsman Adjoint (personal communication 2005)

Rwanda has received considerable amounts of aid since the genocide of 1994. Donors have continued to support the country, encouraged by the government's record of good governance and significant achievements in rebuilding the nation, securing peace and stability and reducing poverty. The government receives direct budgetary support from three donors (DFID, the European Union and the Swedish International Development Agency) Several other bilateral and multi-lateral donors provide assistance in grants and loans, and sector-wide approaches operate in education and health.

Generally, there appears to be quite good donor harmonisation, and the government is strong and willing to take the initiative. For example, the current public-sector reform process was instigated by the government, not by donors.

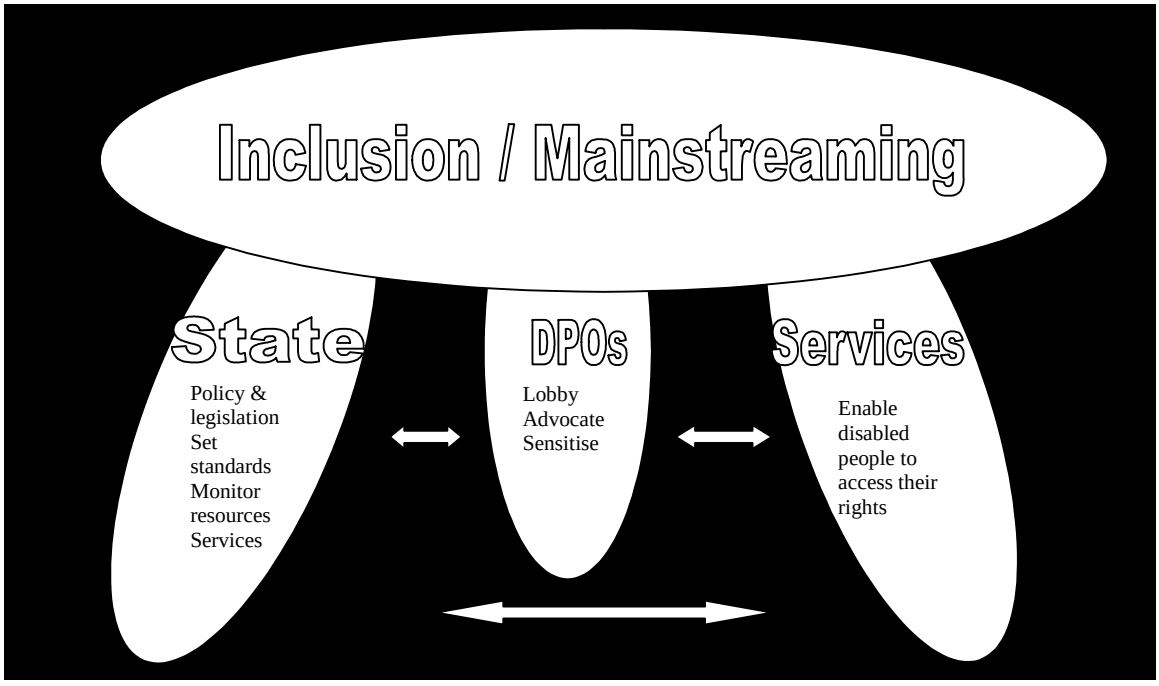
The country saw a new constitution ratified by public referendum in 2003 . National, local and presidential elections also took place in the same year, with voter turnouts of approximately 95 per cent.

Disability and development

To develop and ensure disabled people's rights and equal opportunities, the three key actors need to work in a coordinated and mutually supportive manner:

- the state
- service providers
- disabled people's organisations (DPOs).

The roles and responsibilities of these actors are illustrated in the figure below.



In Rwanda, broadly all of the key components are in place, and there is considerable potential for mainstreaming the needs of disabled people.

The state

The rights of disabled people are specifically mentioned in the new constitution in articles 1,14 and 40 (Republic of Rwanda 2003). The constitution also designates one seat in the house of deputies for a disabled deputy to represent the interests of disabled people. This deputy is elected by the General Assembly of the Federation of Associations of Disabled People and Centres (FACHR), which the government established in 2001. Discrimination against disabled people is also prohibited in the 2001 *Law Instituting Punishment for Offences of Discrimination and Sectarianism* (Republic of Rwanda 2001).

In 2001, MINALOC also prepared a draft Bill on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Although its intentions are good, it was prepared with little consultation with disabled people. It is vague, and it fails to clearly define roles and responsibilities and entitlements for disabled people. However, at the time of writing, FACHR was about to employ a legal consultant with the support of TROCAIRE to work on improving the draft law, drawing on examples of similar legislation in the region. MINALOC was very supportive of this initiative, and all government-employed informants for this study spoke of the importance of enacting specific disability legislation.

Disability is specifically included in the government's planning and policy documents. Its *10 Year National Development Plan* contains a paragraph on disability, committing to put in place mechanisms to:

- facilitate the participation of disabled people in Rwanda's development
- improve accessibility of public buildings
- support services for disabled people
- promote cooperation between associations of disabled people and international organisations
- prepare places for disabled people in decision making institutions.

MINALOC is the main line ministry responsible for disability. It has developed a *National Policy for the Protection of the Handicapped* (MINALAC). The policy is based around six principles that emphasise the participation of disabled people in decisions that affect them and their integration. The objective of the policy is:

> "to give the handicapped equal opportunity as ordinary people so that they may live a better life and participate in their country's development." MINALOC

The actions it identifies are:

- to develop disability policies and laws
- to improve access to education and medical treatment, including disability prevention
- to promote dialogue and sensitise the population
- to promote sport and cultural life for disabled people
- to promote the right to work for disabled people
- to facilitate disabled access to public places.

MINALOC developed this policy without foreign technical assistance, and it was only available in the local language, Kinyarwanda – a clear indication of genuine government ownership. By the time of writing it had been translated into English.

The government recognises disability as a cross-cutting issue, and other key ministries have also dedicated disability sections within their policies and planning documents (for example, the *Education Sector Strategic Plan* (MINEDUC 2003), the *Health Sector Strategic Plan* (MINESANTE 2005), and National Policy for Orphans and Other Vulnerable Children (MIGEPROF, unpublished).

The Government of Rwanda should be congratulated for its consistent recognition of the needs and rights of disabled people in legislation, policy and planning documents. However, words are easy: the real test lies in the implementation. However, here too, despite limited resources, the government has made some progress.

Vulnerable groups budget
Under the 'exceptional expenditure' line in the national budget, MINALOC provides financial resources for vulnerable groups both nationally, and to the provinces. In the 2005 draft budget, RFR300 million are allocated. However, it appears that very little of that money is transferred down to individual districts. Disabled people complained that they saw very little of this money because other vulnerable groups, particularly widows and orphans, were prioritised over disabled people.

There is no suggestion that vulnerable groups budget is not being used for its intended purposes. There are many vulnerable people in Rwanda and as the budget is clearly insufficient to meet all their needs, decisions over priorities have to be taken. However, the budget might be used more effectively if it were transferred directly to districts, where authorities are much closer to the ground and in a better position to identify the most vulnerable individuals and households. Furthermore, it may be worth considering specifically allocating a proportion of the budget – perhaps 5–10 per cent – for disabled people.

District-level support for disabled people
Support for disabled people from district authorities is patchy and variable. During the course of the research, examples of good practice included:

- tax exemption for disabled people, helping them to gain the most benefit from small trading activities
- subsidised health care
- assistance with shelter.

However, it was also reported that in one district wheelchair users were banned from using the main road, and one individual complained that a senior district official had threatened to run her over if he saw her using her wheelchair on the main road again.

National Assistance Fund for Needy Survivors of Genocide and Massacres in Rwanda (FARG)
This fund was established by a specific statute in 1998. Five per cent of the national budget is allocated to the fund every year, along with 1 per cent of the revenue from income tax. In addition, every adult is required to pay RFR100 each year, to the fund, but this has been difficult to collect. The fund has also received external support from donors.

The aim of the fund is to support needy survivors in building sustainable livelihoods, via education, health, housing and social rehabilitation programmes. The Executive Secretary of FARG commented: “All of our survivors, I suppose, are disabled.” However, a survey by FARG estimated that 300,000 of the genocide survivors were disabled. At least 13,000 have been seriously wounded, 500 have lost one or more parts of their body, 3000 are blind and 4000 are deaf (FARG Leaflet 2002).

Approximately 70 per cent of the fund has been spent on education, paying for school fees for secondary school students and for materials. Disabled survivors are probably less able to benefit from this assistance than non-disabled survivors because given the difficulty that disabled children tend to have in accessing education, few are likely to find themselves in a position to attend secondary school. More than 180,000 survivors have received assistance with medical care, and many of them will have been disabled. Some individuals with particular needs have been referred overseas for specialist treatment and surgery. They have included many women with fistulas – a particularly disabling condition – that developed as a consequence of rape and sexual violence.

FARG represents one of the key support mechanisms for disabled people in Rwanda, but it only supports disabled genocide survivors. Furthermore, the future operational effectiveness of FARG is likely to be adversely affected by the deep cuts to staffing that the fund has experienced under the public-sector reform process.

National Demobilisation and Re-integration Commission (NDRC)
The NDRC was established in 1997. It is supported by government funds, but most of its resources come from a World Bank loan and a grant from the European Union (EU). In 2003, the commission established a medical rehabilitation programme. It estimates that 8,400 demobilised soldiers are chronically ill or disabled and has established a screening mechanism based on similar systems used by insurance companies, the WHO and other African countries, to assess the degree of an individual’s permanent disability.

The programme screens individuals and then issues them with a Permanent Disability Certificate (PDC), which entitles them to a one-off lump sum payment ranging from RFR100,000 for those with a disability rating of below 30 per cent to RFR500,000 for individuals deemed 90–100 per cent disabled. It also considers other factors, such as access to land, in deciding the final amount to be received. The certificate also entitles the individuals to free treatment for their disability.

The NDRC estimates that approximately 200 demobilised soldiers are 90–100 per cent disabled and will require long-term care. These individuals are currently entitled to free medical care for all ailments, not just those related to their disability. The commission also hopes the government will enact a specific law on protecting the rights of disabled soldiers, which will include a monthly allowance to those most severely disabled.

With the support of JICA, the NDRC is planning to establish a rehabilitation and training centre in Kigali, with four branches in the provinces, where disabled soldiers can learn activities of daily living as well as vocational and income generating skills. It is anticipated that other disabled people will eventually use these centres, but the priority is disabled soldiers. The commission is linking with FACHR and in 2004 provided RFR80,000 to support the celebrations of the International Day of Disabled People.

In many ways, the NDRC has achieved a great deal in its efforts to support disabled ex-combatants. Demobilising and re-integrating combatants is a pressing issue for Rwanda that has attracted international attention and support. However, the commission's actions are not unproblematic. It has developed its medical rehabilitation programme without really engaging with the wider disability sector in Rwanda. Is disability assessment manual was created without consulting with local disability organisations or DPOs. In addition, although it has established a Social Medical Advisory Committee that includes the director of Handicap International and three representatives of service providers, it has no disabled representative.

FACHR strongly opposes the NDRC's plan to instate a separate law on the rights of disabled soldiers. It also appears to be largely unaware of existing rehabilitation centres that could offer skills training in activities of daily living and income generation for disabled soldiers. Its plan to establish its own centres risks unnecessary duplication, rather than using its resources to build on and enhance existing facilities. The commission's activities are occurring in parallel to developments in the disability sector, and are contributing to a multi-tiered system of support to disabled people in which disabled soldiers and genocide survivors are given preferential treatment in accessing services and support above all other disabled people.

National Youth Council (NYC)
The National Youth Council was established under the new Rwandan Constitution. Representatives are elected at cell, commune, district, province and national level. The membership is responsible for electing the two designated youth deputies in the House of Deputies. The council defines 'youth' as anyone between 14 and 35 years old. It acknowledges that given that 66 per cent of the Rwandan population are under 25 years old, a high proportion of Rwanda's disabled people are also likely to be within the youth bracket, so it is seeking funding to establish a Head of Section post for disability, and to support activities such as awareness raising, income generation and skills training.

The reach of the NYC is potentially enormous. It could play a significant role in reaching out to disabled young people at the grassroots, listening to their needs, and helping them to integrate and play an active role in the development of the nation.

Office of the Ombudsman
Under the current constitution (Republic of Rwanda 2003), a head ombudsman and two deputies were established and a separate law was enacted defining the office's role and function. The ombudsman's role is to hear and investigate complaints from citizens about issues of corruption and injustice. So far, the office has not received any complaints from disabled people. However, if the draft disability law were enacted, the office would have some responsibility for ensuring compliance. The deputy ombudsman said that if a disabled child were refused access to a school because of their disability, it would be within the office's remit to investigate this case.

National Human Rights Commission (NHRC)
The NHRC was established in 1999 to promote and raise awareness about human rights and to investigate human rights abuses. Currently it has no special programmes for disabled people, but it includes disabled people in all its activities. Cases are cross-referred between the NHRC and the Office of the Ombudsman. Again, so far, no cases involving disability have been received. At the time of writing, the NHRC was planning to conduct research into how far the right to education was being observed in Rwanda, and was interested to hear of cases where disabled children had been refused access to school.

Disabled people's organisations

DPOs are organisations run and owned by disabled people, though non-disabled people may be members or employees. DPOs are essential to represent disabled people and to advocate for their rights with government and society in general. Because of the legacy of the genocide and conflict, civil society in Rwanda is weak, and Rwandan DPOs are no exception.

Federation of Associations and Centres of Handicapped People in Rwanda (FACHR)
FACHR was established by MINALOC in 2001 to act as the umbrella organisation of, and for, disabled people. The membership includes associations of disabled people (DPOs), national disability organisations and centres, and special schools. FACHR has representatives at national and provincial level and hopes to decentralise to districts in the near future. There is an Annual General Assembly, which elects the National Executive Committee and is also responsible for electing the disabled deputy in the House of Deputies. There is a small secretariat with two members of staff. VSO has also just placed a volunteer with FACHR to build its organisational capacity.

Innocent Twagiramungu, disabled representative in the House of Deputies

FACHR is still relatively new. Despite being weak and under-resourced, it has encouraged the formation of associations of disabled people throughout the country. Self-help groups are mushrooming, but few disabled Rwandans – perhaps 80 per cent – are members of an association yet.

FACHR is working with MINALOC on developing the draft disability law, and is consulting with its members. All its main associations and centres are members, and it is fully recognised as the national representative body for disabled people by all actors in the sector. However its relationship and status with the government is not clear. In a sense it is a quasi-government body, receiving financial support from MINALOC, and the secretariat is located with the MINALOC building.

FACHR has a critical role to play in coordinating the sector, working through its membership to raise awareness on disability issues and representing disabled Rwandans within government. It needs considerable support, both in terms of resources and capacity building and organisational development, if it is to fulfil its role effectively.

Rwandan Union of the Blind (RUB)
The RUB was started in 1994 by blind returnee Rwandans. It has more than 2000 members and is Rwanda's representative in the World Blind Union. The RUB is well organised and has been receiving some support from external donors, such as the Danish Association of the Blind, Handicap International and the Swedish Organisations of Disabled Persons International Aid (SHIA). It has a rehabilitation centre in Kigali Ngali where blind people can learn activities of daily living, literacy and numeracy and vocational skills. The union also encourages the establishment of small associations of the blind throughout the country. However it needs further resources if it is to continue and expand its vital work.

Recently, three individuals disaffected with the RUB has established the Blind People's Association (BPA). This group claims to have 200 members and has received funding from the Belgian government to buy musical equipment to establish a band and teach music to blind people as a way of earning a living.

Rwanda National Association of the Deaf (RNAD)
The RNAD was set up in 1999 and is affiliated to the World Federation of the Deaf. It has received a small amount of support from Handicap International, which paid for an office and furniture, however this support has now ended and at the time of conducting the research it seemed likely that the RNAD would be evicted.

The RNAD aims to improve the living situation for deaf people. It has developed a clear action plan but lacks the capacity to develop this into a formal funding proposal, and without funds the RNAD is unable to implement its plans.

The RNAD is particularly concerned about raising awareness of HIV/AIDS among the deaf community and have approached organisations working in this area for support, but they have been unsuccessful.

Within the RNAD there is the Rwanda Association of Deaf Women (RADW) in Kigali. The group is very small and without funds. Nevertheless, it tries to reach out to deaf women, providing moral support and community. It also teaches sign language and sewing skills.

Financial and technical support is needed to enable the RNAD to play its vital role in representing deaf people, promoting and developing the use of sign language and raising awareness on deafness.

General Association of the Handicapped in Rwanda (AGHR)
AGHR is Rwanda's oldest DPO, established in 1979 by a group of educated disabled people who came together to find ways to help their less fortunate peers. The organisation was almost completely destroyed in 1994 as only three members of the committee survived the genocide. In 1996, the association was reformed but it was not until 1998 that it was able to resume activities, with the support of the UK NGO, Action on Disability and Development.

AGHR conducted a survey and developed a five-year action plan focusing on sensitisation, support for disabled women, education for disabled children and income generation, and capacity building of the organisation.

A funding shortage has meant that currently, AGHR only focuses on sensitisation, education and income generation. Its work has involved:

- encouraging the establishment of 16 self-help groups
- supporting the education of 53 disabled children
- providing vocational training in sewing and electronic repairs
- giving support to establish small businesses
- developing micro-credit schemes within associations.

It currently receives funding from the Vatican and Caritas.

Services

Services for disabled people include providing assistive devices, medical rehabilitation, physiotherapy, education and training. These services are essential to enable disabled people to participate and access their rights. Throughout the world, they are offered by a mixture of state and civil-society providers. Governments in the developed and the developing world alike, are never likely to be able to provide all the services that disabled people need, and in many cases, such as in the areas of long-term and residential care, civil society organisations are often much better qualified.

The state has the following duties:

- to promote and protect the rights of disabled citizens
- to set and monitor standards in service provision
- to seek to ensure that disabled people wherever possible can access mainstream state services, such as health and education
- to provide some specialist services and resources for specialist services.

Civil society service providers need to work with state mechanisms, adding value, rather than establishing parallel structures and systems. In developing countries, civil society organisations – particularly international disability NGOs – play a critical role in building the capacity of the state to gradually resume more responsibility for specialist services.

In Rwanda, the balance between state and civil society in service provision is generally quite good given the limited resources of the state. Services for disabled people in the areas of health and education are addressed in the following sections. There are two main problems: the relatively severe shortage of specialist services, particularly for deaf, the mentally handicapped and people with mental health problems, and the lack of coordination in current service provision. Improvements in the latter would go a long way towards resolving the former.

During the course of the research, it was not possible to map existing services. However, accurate mapping of services is desperately needed. There are a number of well-known rehabilitation centres and special schools, but during the field visits, it emerged that there were other small centres and organisations providing mainly education and skills training that appeared to be unknown to FACHR. It also became apparent that duplication and lack of cooperation is another issue. For example, in most provincial towns physical rehabilitation services are available in district

hospitals and in special centres run by the local NGO One Love, but there are no links between the two.

Deaf chidren learning sign language at a special class at the Centre des Artisans Handicapes in Gisenyi – an initiative of which FACHR and MINEDUC were unaware

The lack of information about services also prevents proper state regulation and monitoring. But even now, there is confusion over ministry responsibility and oversight of services. Centres had generally weak links with government, and were unclear about which ministries (whether MINALOC, MINEDUC or MINESANTE) they should relate to. Some centres and special schools do provide long-term residential care for a few disabled children, but at the time of writing it seemed likely that MIGEPROF's work towards developing national standards for institutional care would not cover these children.

Health

The Ministry of Health (MINESANTE) is in the process of developing with donors a sector-wide approach ('SWAp') for the sector and has recently published its *Health Sector Strategic Plan 2005–09* (MINESANTE 2005).

The government budget allocation to health has increased substantially in recent years, and in 2004 the percentage of recurrent government expenditure allocated to health was 6.6 per cent. However, despite this, Rwanda is considerably off-track in meeting the Millennium Development Goals (MDGs) for infant, child and maternal mortality. Maternal mortality remains one of the highest in the world, at 1,071 per 100,000 births. Immunisation programmes performance is relatively high for the region, with 85 per cent coverage rate but nevertheless, Rwandans are most likely to die from poverty-related preventable diseases. Malaria is the leading cause of mortality and of 50 per cent of morbidity in health facilities. HIV/AIDS, acute

respiratory infections, diarrhoeal ailments and tuberculosis are the other main causes of mortality and morbidity.

The health sector infrastructure is generally satisfactory, with almost 60 per cent of the population living within 5 kilometres of a health centre. However, the lack of trained medical personnel is a major challenge. There is one nurse per 3,900 people and one doctor per 50,000 inhabitants. Furthermore, in the public health system, personnel are poorly motivated and there are large disparities between the provinces and rural and urban areas (MINESANTE 2005).

Disability and health
Disability relates to health in three main areas:

- access to mainstream health services by disabled people
- access to specialist rehabilitation services for disabled people, such as corrective surgery and assistive devices (including prostheses, orthoses, wheelchairs and mobility devices, and spectacles)
- prevention of disabilities.

Access to mainstream health services
Disabled people generally require more health services than non-disabled people. The nature of their impairments often leaves them more vulnerable to infections and complications requiring medical treatment.

Broadly, disabled people will share the same difficulties that non-disabled Rwandan face in accessing health care, but there are some differential factors. First, disabled people may need assistance to reach health facilities, and those with mobility problems will not find accessibility features in most facilities. There are currently no accessibility guidelines covering the construction or rehabilitation of health facilities. Second, disabled people may be deterred or delay seeking medical help because of the need for assistance from a member of the family and lack of confidentiality. This has been highlighted as a significant factor in relation to testing for HIV/AIDS (Yousafzi and Edwards 2004). Finally, households may prioritise health care for non-disabled members over disabled members.

Access to specialist rehabilitation services
An estimated 4.8 per cent of Rwanda's disabled population have moderate or severe disabilities and 1.5 per cent of those with physical disabilities are in need of urgent rehabilitation services, with 0.5 per cent needing assistive devices. However only 5 per cent of disabled Rwandans are able to access the services they need (MINESANTE 2002).

There is a Bureau for Technical Rehabilitation and Prevention of Blindness within MINESANTE. The bureau is responsible for coordinating services and planning. In 2002, it produced a National Plan for the Rehabilitation of Disability and a National Plan for the Prevention of Blindness (MINESANTE 2002b), in cooperation with civil society service providers. These two plans have been incorporated in the draft HSSP. However since 2002, no real progress has been made on the National Plan for Rehabilitation of Disability, due to lack of funds. The National Plan for the Prevention of Blindness has seen some implementation from support from the Christian Blind Mission (CBM).

Current provision of specialist rehabilitation services
Physiotherapists are trained in the Kigali Institute of Health (KIH), but there are very few physiotherapists qualified to the highest level. Handicap International France

has trained 12 assistant physiotherapists, and physiotherapy training is also offered at the Inkuru Nziza Centre in Kigali, run by CBM, and at Gatagara, where blind physiotherapists have been trained. There is no school of prosthetics and orthotics (P&O) but Handicap International has trained 11 P&O assistants. Local NGO One Love has also trained up P&O staff, some of whom have received training in Japan.

Specialist rehabilitation centres in government facilities are found in:

- Kigali University Hospital (CHUK)
- Butare University Hospital (CHUB)
- Kanombe Military Hospital in Kigali
- Gahini Hospital (Umutara)
- district hospitals in Gihundhe (Cyangugu), Gisenyi, Ruhengeri, Byumba, Kigeme (Gikongoro), Kibuye and Kabagayi (Gitarama).

Orthopaedic surgery is available in all the above facilities except the district hospitals. CBM also periodically organises visiting surgical teams from overseas.

There are three **referral hospitals** where patients can receive a higher level of medical intervention: CHUK, CHUB and Kigali Central Hospital.

Rehabilitation services are also provided by local NGO One Love in all provinces – either in their own centres, or, in three provinces, in mobile units. However, these services are constrained by a lack of funding. The Gatagara Centre in Gitarama offers physiotherapy, orthopaedic surgery and P&O.

Mental health facilities are extremely limited. The national Neuro-Psychiatric Hospital in Ndera, near Kigali, is the main centre. There are seven centres providing support to people with mental handicaps but only one is outside Kigali.

Community-based rehabilitation (CBR) services are offered by approximately 30 local and international NGOs and faith-based organisations. However, the CBR approach in Rwanda is very limited, and appears to consist of little more than outreach activities. Communities are not being encouraged or trained to develop their own systems to support disabled members.

Services for the blind and visually impaired are mainly supported by CBM. It is estimated that there are 64,736 blind people in Rwanda. Of these, 32,368 are blind due to cataracts and 9,708 due to glaucoma. There are 404 approximately blind children and 194,194 people with low vision. An estimated 3.6 per cent of the population is estimated to have an eye problem requiring surgical or medical intervention, but the majority have no access to eye care or treatment (MINESANTE 2002b).

Eye care centres and clinics are located in CHUK, CHUB, Gitarama Hospital and Kanombe Military Hospital. Foreign eye surgeon teams also carry out visits, organised by CBM. In 2001, only 400 cataract extractions were performed. In the private sector, there are two opthamologists and two optometrists, all in Kigali. One CBR programme carries out screening of visually impaired patients in five provinces. Equipment for people with low vision is extremely limited. (MINESANTE 2002b)

There are no audiologists or organisations offering services for deaf and hearing-impaired people. There are no services at all for deaf-blind people, and their condition is barely recognised.

MINESANTE supports these services by paying the salaries of some staff working in government facilities and providing some materials. However, rehabilitation services are overwhelmingly funded by international NGOs. It is anticipated that under the HSSP there will be some additional MINSANTE support, but services will still heavily rely on international NGO funding.

Government facilities charge user fees, but these do not come any way near to covering the costs. Furthermore, the revenue obtained by rehabilitation centres is not ringfenced, and is usually diverted to other priorities in the hospitals concerned. The financial sustainability of these services is deeply compromised.

The Mutuelle system of health insurance currently covers only 7 per cent of the population but MINESANTE plans to expand the system nationally. Currently only the Mutuelle Fund for public sector employees covers rehabilitation and eye care treatment. This is excluded in all other systems. Government and NGOs subsidise membership of Mutuelle schemes for the poorest in some systems, but currently disabled poor people tend not to be benefiting from these subsidies.

HIV/AIDS and disability

A recent report (Yousafzi and Edwards 2004) on HIV/AIDS and young disabled people in Rwanda found that most were aware of the disease but that their knowledge on prevention and transmission was weak. Most relied on the radio for information.

There was a general assumption in Rwandan society that disabled people did not have sex, or at least that they had less sex than others. This had led a minority to believe that sex was safer with a disabled partner. Disabled people were found to be particularly vulnerable because of their poverty and their difficulty in forming stable relationships and many – particularly girls and women – were at high risk of sexual abuse. Disabled young people did not use HIV services because of the difficulty in reaching them and because of the lack of privacy, because most needed someone to assist them to access such services.

Research for the present study backed up these findings. Informants consistently highlighted the need for better information on HIV/AIDS for disabled people – particularly those who were deaf or blind.

Disability prevention

Malnutrition, limited access to antenatal care, obstetrical services and attendance by skilled midwives at births are major causes of disability, as is the general lack of access to timely and appropriate health care. The HSSP has set targets for improvements in all these areas, including increased coverage of vaccination programmes. However, specific plans on disability prevention and education are generally lacking. Few local and international NGOs offer disability prevention education programmes.

SWOC analysis of health and disability (cont. page 39)

Strengths	Opportunities
• Generally good geographical spread of rehabilitation services • Support from international and local NGOs for rehabilitation • MINESANTE National rehabilitation plans	• Mutuelle systems expansion • Sector-wide approach ('SWAp') for health and HSSP recognition of disability and mental health

for disability and blindness (MINESANTE 2002a and 2002b) • MINESANTE dedicated bureau • MINESANTE support for salaries and some materials in rehabilitation centres • Plans for mental health, physical rehabilitation and blindness in HSSP • Policy ownership of disability rehabilitation services by MINESANTE	
Weaknesses • Access to rehabilitation services available to only approximately 50 per cent of disabled people • Limited services available, heavily dependant on NGO support • Extremely limited services for mental health • No P&O school • Lack of funding from MINESANTE • No services for deaf and hearing impaired • User fees for rehabilitation services not ring fenced	**Constraints** • Lack of trained personnel • Low salaries for many personnel • Disability services not a priority

In many countries in the world, rehabilitation services fall under the remit of social welfare ministries, which often are under funded and have low capacity. It is very significant that in Rwanda, MINESANTE has responsibility for such services, because in many countries responsibility lies with the ministry of social welfare. MINESANTE has fully acknowledged this responsibility by instating its specialist bureau and developing national plans that have been incorporated in the HSSP. However, its current support for such services is extremely limited, and is overwhelmingly dependent on international and local NGO support.

It is extremely unlikely that MINESANTE will be able to provide adequate services for disabled Rwandans in the short or medium term. Nevertheless, it is critical that all stakeholders should work towards building its capacity in terms of financial and human and material resources, to enable it to assume such responsibility in the future.

Education

Background

Article 40 of the Rwandan Constitution affirms the right of every citizen to education. It also states:

> "The State has the duty to take special measures to facilitate the education of disabled people."
> (Republic of Rwanda 2003, p 72).

Primary education is free and compulsory. The national, English Language paper, *New Times* reported that primary school enrolment hit 90 per cent in January 2005 (*New Times* January 14–16, 2005). However, quality is a major concern, with low completion rates (38.11 per cent of the 1998–2003 cohort completed their studies). There are also high repetition (20.6 per cent) and dropout rates (15.2 per cent). There is a shortage of qualified teachers, a high pupil–teacher ratio (65.8 per cent)

and a lack of textbooks. In 2002, gross enrolment at secondary level was only 13.9 per cent, but 48 per cent of secondary students were girls (MINECOFIN 2004).

There are six higher education institutions, and despite a rapid expansion in institutions, transition from secondary to tertiary education is still very low and access from the poor households is limited (MINECOFIN 2004, p 50). Provision for technical education is also limited, and youth training centres need rehabilitation.

Education for disabled children and adults

The rights and needs of disabled people are recognised in the *Education Sector Strategic Plan 2004–08* (MINEDUC 2003). One of the seven goals of the plan is:

> "to eliminate all the causes and obstacles which can lead to disparity in education be it by gender, disability, geographical or social group."
> (MINEDUC 2003, p 8)

The plan commits the Ministry of Education, Science, Technology and Scientific Research (MINEDUC) to develop a policy on special educational needs (SEN). This includes, at primary level, to:

- train 20 SEN teachers by 2008
- open two new SEN centres
- include a SEN component in teacher training colleges.

At secondary level, five secondary schools are to pilot SEN teaching, with five SEN-trained teachers in each. However, so far, no progress has been made on any of these planned commitments (MINEDUC 2003).

In 1997, MINEDUC established a Special Needs Department. One of the department staff is a qualified SEN teacher who trained at the Ugandan National Institute of Special Education (UNISE) and at the University of Birmingham, in the UK. Five other SEN teachers had also received SEN training at UNISE in the past, but none of them were working in SEN education. When they returned there were no SEN posts for them, so they had moved on to other jobs in MINEDUC and in the NGO sector.

Historically, educational provision for disabled children has been within separate special institutions provided by private organisations, charities and the church. This is still overwhelmingly the case. Currently, there is limited understanding of, or interest in, promoting and developing a system based on the principles of inclusive education within MINEDUC. There is one secondary school where blind students have been integrated – Gahini School (see 'Inclusive education incorporating blind students below), but there are seven main special school facilities:

- Butare School for the Deaf
- Butare Secondary School (for mixed disabilities, deaf and visually impaired)
- Rwamagana Gatagara Primary School, Kibungo Province (for visually impaired)
- Rwamagana Primary School, Gitaram (for physical disabilities)
- Amizero Centre, Kigali (for children with intellectual disabilities)
- Nyamirambo School, Kigali (for the deaf)
- Rwamagana Centre, Kibungo Province (providing senior six vocational training for blind students).

These facilities are all supported by private organisations, but MINEDUC pays the salaries of some of the teachers and gives limited assistance in terms of materials, equipment and training. They are the responsibility of the Special Needs Department,

which seeks to coordinate and monitor their operations. In addition, there are other centres for disabled people that provide education for disabled children and literacy classes for disabled adults.

Inclusive education incorporating blind students

Gahini Secondary School started to accept blind and visually impaired students in 1997, in cooperation with the Rwandan Union of the Blind. There are currently 42 such students. The initiative came from the then school principal, who is now the head of special needs education at the Kigali Institute of Education. Teachers and students at the school are encouraged to assist the visually impaired students, but only one teacher (who is himself blind) who can read Braille. The visually impaired students study the general literature course and are given additional support and materials after class by the blind teacher.

While the school has clearly been a success in changing attitudes towards blind people and encouraging a sense of independence and achievement among the blind students, there are problems. The blind students complain of the difficulty in getting adequate notes in Braille, and say that the teachers and students do not always make efforts to accommodate their needs, sometimes complaining about the noise in class from the Braille machines. The school has succeeded in integrating visually impaired students but not yet in fostering a genuinely inclusive atmosphere. However, as the only school of its type in the country, and in the way in which it has grown, with virtually no external support, it deserves significant recognition and still has the potential to act as a model of good practice.

Systems of special schooling are expensive. They require disabled children to live away from home and isolate them from non-disabled peers, and they can never meet the demands for education for all disabled children in a country. The Special Needs Department estimates that only 0.5 per cent of the disabled children in Rwanda can be catered for in the current special school system.

At the time of writing, the Special Needs Department was about to undertake a survey, supported by DFID and UNICEF, to gather data on the number of disabled children in and out of school. The National Human Rights Commission is also planning research on the implementation of the right to education for all groups in Rwanda. It is likely that some children with mild and moderate disabilities are attending mainstream schools. However, there is no sensitisation, information or training available for teachers to help them make sure that these children are not just physically present in schools but are actually receiving an education that meets their particular needs. It is reasonable to conjecture that disabled children are likely to be over-represented in the number of children who drop out or repeat.

The Special Needs Department has been approached by parents of disabled children who have been refused access to schools – particularly secondary schools – by principals. Other disabled children have been required to leave school because they have repeated several times. Some special schools are making limited attempts at integrating disabled children into mainstream schools, but this is done on an individual basis with little or no follow-up, and minimal support and sensitisation for teachers.

In 1999 and 2000, MINEDUC, working with UNESCO, employed a consultant to examine special needs education. The subsequent reports estimated the number of disabled children at approximately 400,000 and made a number of recommendations including:

- to development a SEN policy

- to train SEN teachers
- to strengthen the Special Needs Division
- to develop a pilot inclusive education programme
- to establish a SEN unit in the Kigali Institute of Education (KIE).

Only the last recommendation has been implemented (Kristensen 1999 and 2000).

The lucky few? Students at Gatagara Special School

It is strongly recommended that MINEDUC develops a SEN policy, with a central focus on inclusive education. This inclusive approach is globally recognised to be the preferred way to meet the educational needs of disabled children, and to build an inclusive society. Inclusive education is a method of achieving education for all and improving the quality of education for all learners.

Special schools do have a place in the education system: the educational needs of severely disabled children cannot always be met in mainstream schools. Furthermore, special schools can act as critical resource centres for mainstream teachers. However, inclusive education programmes can successfully be implemented at low cost in developing countries, with resulting improvements in enrolment, drop-out and repetition rates.

The experiences of Laos, Lesotho and Cambodia in particular, provide potential models of inclusive education. At the time of writing, the Imfundo team at DFID was working on developing information communication technology (ICT) solutions for the education of visually and hearing-impaired children in sub-Saharan Africa. In particular, it was assisting with the Ghana Education Service to develop inclusive education.

The Government of Rwanda prioritises ICT as a cross-cutting issue in the PRSP ref], and it vital to ensure that these solutions are embraced to meet the needs of disabled

Rwandans. Integrated education could be the key way to improve the quality of the Rwandan education system.

SWOC analysis of education sector in relation to disability

Strengths	**Opportunities**
• The Special Needs Department • Recognition of the rights and needs of disabled people in the constitution and the ESSP • A system of special schools linked to MINEDUC • The SEN unit at KIE • Existing MINEDUC support for special schools (training, teacher salaries, materials and equipment) • Gahini School	• MINEDUC/UNICEF survey on access to education for disabled children • The government's commitment to EFA • The DFID/Imfundo team's work on ICT solutions for hearing and visually impaired children • UNESCO's flagship campaign for inclusive education
Weaknesses	**Constraints**
• No SEN policy • Existing SEN-trained staff not working in SEN education • No system of inclusive education and limited awareness of the approach • Lack of data on disabled children's access to education	• Negative attitudes towards disabled people • Overstretched education system • Limited awareness of needs of disabled children in education planning • Low quality of the Rwandan education system • Lack of qualified teachers • Discriminatory attitudes of some school principals

5. Analysis, recommendations and conclusion

> "Perceptions of inequality and social exclusion in the broadest sense have been a major feature of Rwanda's history and were the basis for the manipulation of the Rwandese people and ethnicisation of all aspects of life which laid the foundation for the genocide of 1994. Reducing poverty, inequality and building an inclusive society must be the basis of unity and reconciliation."
> (PRSP 2002, p 72)

> "Disability is an issue everyone is aware of, but very little is done."
> (Interviewee)

The Government of Rwanda is committed to reducing poverty and building an inclusive society in which human rights are promoted and protected. It should be congratulated for recognising that addressing the needs of disabled people is an integral part of achieving its goals for the country. There is genuine political will at senior levels to assist disabled people.

In many ways, the government has taken the lead, by:

- specifically enshrining rights of disabled people in the Constitution and other legislation
- designating a place for a disabled deputy in the parliament
- establishing and supporting a national disability body
- developing a national disability policy
- ensuring that disability is included in all key policy and planning documents.

All the key components are in place in Rwanda to enable disabled people to access their rights and participate fully in society. In addition to the considerable government interest in the issue, there is a nascent but nonetheless burgeoning disability movement and a well-established and committed range of CSOs providing services. Nevertheless, the situation of the average disabled Rwandan is currently rather bleak.

Rwandan society places little value on disabled people, they are seen as useless and incapable and are stigmatised and discriminated against. They are over-represented among the poor, but their disability means that they experience poverty more intensely than their non-disabled peers, and they have fewer opportunities to escape from poverty. Lack of access to basic assistive devices prevents many from realising the full potential of their assets. Largely excluded from mainstream development initiatives, they become trapped in a vicious cycle of poverty and dependence, and are forced to conform to stereotypical role of the passive victim.

As Rwanda emerges from the humanitarian and emergency crisis created by the genocide and enters a long-term development phase, it is critical that disabled people are given equal priority with other vulnerable groups. Failure to transform the real political will of the government on behalf of disabled people into concrete action will result in a brake on Rwanda's development. Education for all cannot be achieved unless disabled children are properly catered for. Disability affects not only the individual but the whole household, and poverty reduction will be hampered if disabled people are neglected. A genuinely inclusive society cannot be realised if disabled citizens continue to be marginalised and their potential overlooked.

Presented below is an analysis of the disability sector in Rwanda, followed by recommendations for building on what has already been achieved.

SWOC analysis of the disability sector in Rwanda (cont. p 46)

Strengths	**Weaknesses**
• Strong government recognition of the rights and needs of disabled people (legislation, policies, MP) • Recognition of disability in national and sectoral plans • Dedicated units in MINEDUC and MINESANTE • Government support (budget for vulnerable groups, FARG, Demobilisation and Reintegration Commission) • Improving attitudes towards disabled people (Para-Olympic bronze medal) • Establishment of FACHR • Growing number of associations of disabled people • Political will to implement disability legislation • Good geographical spread of rehabilitation services • Range of dedicated CSOs and service providers (international and local NGOs, churches)	• Limited and overstretched government resources (no dedicated budget for disabled people) • Patchy and variable government support for disabled people at district level • Lack of coordination and cooperation amongst CSOs in the sector and with government systems and processes (for example, the Demobilisation and Reintegration Commission, two draft laws on disability) • Lack of data on the scale and prevalence of disability, the number of disabled children in and out of school, and mapping of services • Lack of specific legislation protecting and promoting the rights of disabled people and defining benefits • Weak and unrepresentative DPOs • Lack of access to education with few improvements since 2000 • Cost barriers to specialist rehabilitation services • Very limited services for mentally handicapped, those with mental health problems and the blind • No services for deaf people and deaf-blind people • Sustainability of services (education and health) questionable • Lack of national standards for care and rehabilitation services
Opportunities	**Constraints**
• Planned surveys (the household survey, CBM/MINESANTE disability survey, UNICEF/DFID/MINEDUC survey on education for disabled children) • National Youth Council • MINALOC's development of social protection policy and system • National Human Rights Commission and Ombudsman • VSO's expanding support to disability • Planned reform of the labour law	• Negative attitudes towards disabled people (discrimination and social exclusion) • Dominance of a 'charity attitude' towards disability in Rwanda among disabled and non-disabled people • Legacy of genocide (weak civil society, trauma, social divisions, poverty) • Limited awareness of government policies at local authorities and among disabled people • Public sector reform process (for example, staffing cuts to FARG) • Limited understanding of, and interest in, inclusive education • Unclear lines of responsibility between ministries for different aspects of services and care for disabled people • Limited government resources and other vulnerable groups being prioritised over

	disabled people • General failure of development programmes and initiatives to reach the very poorest, and disabled people in particular (for example, HIMO, Ubedehe, micro-credit)

Recommendations

Enact specific disability legislation
Specific legislation enshrining and promoting the rights of disabled people is critical. It should define clear roles and responsibilities for government and civil society. It should also establish accessibility criteria for new buildings, and designate certain benefits and entitlements. There should not be separate legislation for disabled ex-combatants: their particular needs can be recognised with a single disability law covering all disabled Rwandans. Such legislation could harmonise existing legislation and enhance the engagement of institutions like the Office of the Ombudsman to act on behalf of disabled people.

Strengthen coordination and disabled people's organisations
The effectiveness of the disability sector is being undermined by a lack of coordination within government ministries and with, and between, civil society actors. Such coordination could be led by MINALOC, or preferably, by FACHR.

FACHR's current status is somewhat nebulous. The organisation is not a genuine DPO because its membership includes centres as well as associations of disabled people. But its constitution does not currently allow international disability organisations as members. It was established by government and supported by MINALOC, and is located within MINALOC's building. In a sense, it is a quasi-governmental body. Perhaps within any specific disability legislation its status could be defined as such, and it could be mandated to act as the national coordination and advisory body on disability. The Disability Action Council in Cambodia (see box) could provide a potential model.

(cont. p 47)

The Disability Action Council (DAC) was established by the Cambodian government as a semi-autonomous government body to act as the national advisory and coordination organisation for disability and rehabilitation. The DAC provides a forum to bring together all stakeholders in the sector. The governing board comprises representatives from the leading government ministries, DPOs, NGOs, donors and the business community.

A permanent secretariat was established within the Ministry of Social Affairs. The secretariat facilitates a number of committees and working groups, covering areas such as women and children with disabilities, medical rehabilitation, legislation, community work with disabled people and vocational training. The committees act as a mechanism for information-sharing, coordination and cooperation.

The DAC's key achievements include:
- creating a single classification system for disability, used in all data gathering exercises

- reducing duplication and improving geographical spread of services
- representing Cambodia at all international disability conferences and meetings
- acting as a central resource and information centre for the sector.

The DAC receives some support from the government but its core costs are currently covered by an international donor. However, some funding comes from membership fees. International NGO members pay 2 per cent of its annual budget but fees are waived for organisations with few resources.

If FACHR were to fulfil such a role, it would need considerable organisational development and capacity building, as well as increased support. If it establishes district level representation as it hopes to, it could also facilitate the distribution of any future designated budget allocation for disability. If its status was as a semi-government body, it could work with district authorities to identify and disburse small grants to associations of disabled people for development initiatives.

Rwandan DPOs are currently weak and not representative. They need to be strengthened so that they can effectively advocate for the rights of disabled people with government, donors and society as a whole. A strong disability movement is essential to ensure that any future disability legislation is properly enforced and implemented. FACHR's strong links with the government compromise its ability to really hold the government to account, however it should continue to act as a body to promote and facilitate the strengthening of grass-root DPOs.

International NGOs currently involved in the sector, such as Handicap International, CBM and VSO, should consider how they can give greater support to the development of Rwandan DPOs alongside continued support to service provision. VSO's placement of a volunteer within FACHR is greatly welcomed. As VSO considers how to develop its disability programme, priority should be given to further volunteer placements that can strengthen DPOs.

The Government of Rwanda needs to clarify ministerial responsibilities for disability. There is insufficient government overseeing of centres and special schools. This is partly because of lack of information about services (see below). Nevertheless long-established facilities seem unclear about which ministry they should link with. There is a real risk that vulnerable disabled people – particularly disabled children and people with mental handicaps – could fail to be adequately protected because of the lack of clear ministerial supervision and monitoring of special schools and centres. There is also need to establish minimum standards for disability services.

Improve data collection and information on disability

Government and NGO planning for the sector is hampered by the lack of data and information. There is an urgent need to harmonise the various planned surveys (National Household Survey, MINEDUC/UNICEF/DFID survey on disabled children in and out of school, MINESANTE/CBM survey on disabled people). All are PLANNED surveys. A single classification system for disability needs to be established and used by all in future data collection, whether for the national census or for small-scale surveys by NGOs and DPOs. The Cambodian classification system could be a model (see Annexe 6). A comprehensive mapping of existing services is also a priority.

Establish a comprehensive social protection policy with a designated budget for disability and specified benefits for disabled people based on need
MINALOC is eager to harmonise existing social protection mechanisms within a comprehensive single social protection framework. Disability needs to be specifically included within such a framework, with a designated budget allocation, otherwise other groups are likely to be prioritised over disabled people, as currently happens with the MINALOC budget for vulnerable groups.

Currently access to benefits and services is haphazard and not based on need. Disabled survivors of the genocide and disabled ex-combatants are given preferential treatment over other disabled people through semi-government mechanisms, such as FARG and NDRC. Access to services provided by NGOs and faith-based groups depends largely on where a disabled person lives and whether they can physically reach a centre. It is also dependent on resources. Those with sufficient finances can pay for services, or at the very least, can pay for transport to the rehabilitation centres and special schools where they can ask for charitable assistance.

The NDRC's Permanent Disability Certificate screening and assessment system could form the basis of a national disability assessment system that bases benefits and entitlements on the severity of an individual's disability. The NDRC is proposing that ex-combatants with a 90–100 per cent disability rating should receive free medical care and a modest monthly allowance. Such benefits should not be reserved only for ex-soldiers but extended to include all severely disabled people.

In general, the government needs to work towards removing preferential treatment for disabled genocide survivors and ex-combatants and recognise that disability benefits should be granted on the basis of need. If the current budget for vulnerable groups is continued, it should have a specific disability allocation of perhaps 5–10 per cent, and should be disbursed to districts rather than provinces. A strengthened and further decentralised FACHR could work with district authorities to identify local priorities, needy individuals and groups, to receive such government support.

Reduce the cost barriers and improve the financial sustainability of rehabilitation services
Cost is the major barrier preventing disabled people accessing specialist rehabilitation services. Over the next few years, the Government of Rwanda plans to expand the Mutuelle Funds health insurance system. Currently only 7 per cent of Rwandans are part of Mutuelle systems, and the poorest are usually excluded as they cannot afford the fees. Subsidised Mutuelle membership is offered to some. Only the public sector employees' Mutuelle system covers rehabilitation and eye-care services.

In the future, all Mutuelle systems should cover all, or at least part of, rehabilitation and eye-care services. Given that disabled people generally require more health services than non-disabled people, priority should be given to needy disabled people when it comes to subsidising membership of Mutuelle systems.

In addition, monies collected from user fees at government rehabilitation centres should be ringfenced and retained for use for rehabilitation. This would significantly improve the financial sustainability of rehabilitation services.

Establish a national policy on education for disabled children with a strong focus on inclusive education
The MINEDUC/DFID/UNICEF planned survey on disabled children in and out of school is very welcome. MINEDUC needs to use the results to develop a comprehensive policy on education for disabled children. It is strongly recommended that inclusive education should be the central focus of such a policy. Efforts need to be directed at building the knowledge and capacity of mainstream teachers to accommodate and meet the needs of disabled children in regular schools.

Lessons from successful inclusive education programmes in other developing countries, such as Laos, Cambodia and Lesotho, emphasise the need to start small and grow gradually. Training for teachers can initially be relatively basic and short (three-to-five days in Laos and Cambodia) because people learn best by doing, but continued follow-up and support is essential.

Special schools are still important: some disabled children's needs cannot be met in mainstream schools. But the vast majority of children with mild and moderate disabilities can go to regular schools. Special schools need to encourage and support the inclusion of disabled children in regular schools wherever possible, and work with local schools to build their capacity by assisting with sensitisation and basic training for teachers.

Case study: Inclusive education in Cambodia
Inclusive education was introduced in nine primary schools, in 2000. Today, it takes place in 95 schools, in nine provinces.

The programme was closely modelled on the experience of Laos. Teachers undergo a basic three-day training programme. They are then supported by the Provincial Implementation Team (PIT), which is made up of representatives from the Ministry of Education, Ministry of Social Welfare, and disability organisations and DPOs. The team visits schools in the programme every two months. The team members focus on supporting the teachers and improving their teaching methodology. The Ministry of Social Welfare and disability organisation representatives on the PITs identify and assess disabled children in and out of school, refer children for assistive devices and surgery, and take the lead in raising awareness on disability within local communities.

The programme has produced a range of awareness-raising materials. These include a set of four posters giving basic advice to teachers on how to include children with different difficulties (in moving, hearing, seeing and learning) in class. Each poster illustrates five simple ideas for teachers to practice. The posters have become very popular and are found in schools all over the country.

Inclusive education should be seen as a key way to achieve education for all and improve quality in Rwandan schools. Schools in the inclusive education programmes in Laos and Lesotho outperform other schools, with higher enrolment rates and lower repetition and drop-out rates.

Improve access to information and services on HIV/AIDS for disabled people
Disabled informants for this study consistently raised the lack of access to information and services on HIV/AIDS – particularly for blind and deaf people. Government and civil society bodies working in the field of HIV/AIDS need to recognise that disabled people are particularly vulnerable, and take steps to ensure that they specifically include and target them in awareness-raising and information activities.

Continue to support and develop sensitisation campaigns on the rights and abilities of disabled people
Attitudes towards disabled people in Rwanda have improved in recent years, but disabled people still suffer from stigma and the failure of Rwandan society to recognise their abilities. There appears to be considerable discrimination against disabled people in employment. In recent years, several factors have made a significant contribution towards dismantling the traditional charity attitude towards disabled people. They include high-level political support from the President and others, the achievements of Rwanda's disabled athletes in international competitions, and the sensitisation activities of DPOs and disability organisations.

Sensitisation activities need to be supported and developed because, as the Ombudsman Adjoint Bernard Ndashimye put it, "The legal system can provide rights but implementation depends on the mind" (personal communication 2005). The government should be congratulated for the support it has given to awareness raising and to FERHANDIS. It should continue providing this support and encouragement.

The NHRC needs to consider how it can work with FACHR and DPOs to raise awareness on the rights of disabled people. Meanwhile, international NGOs should provide support for sensitisation campaigns and activities.

Development activities and programmes must seek to ensure that they actively include disabled people and do not unwittingly discriminate against them
It cannot be assumed that disabled people with benefit from development activities in the same way as non-disabled people. Research for this study revealed that disabled people are often not informed about development activities going on in their communities, and even if they do know about them, they are routinely excluded from participating. This exclusion is both active and passive.

If development activities are really to reach the poorest, then special efforts need to be made to remove the barriers (attitudinal, environmental and institutional) that prevent disabled people from participating. For example, within the HIMO programme, certain jobs could be specifically allocated for disabled people to fill, such as time- and record-keeping.

Donors also have a clear role to play. First, they need to remember the needs of disabled people when they are design and monitoring their own programmes. Second, they can encourage others to do the same by requiring funding applicants to demonstrate how their planned activities will include disabled people and making sure they refer to disability in their reporting and monitoring procedures.

Conclusion

Rwanda has made extraordinary progress since the genocide, and the country is well placed to make similar progress with regard to disability. All the key components are broadly in place, and the government should be congratulated for its recognition of the needs of disabled Rwandans. All stakeholders in the sector need to work together to support each other and the government, to build on the firm foundation that already exists, and to ensure that commitments on paper are fulfilled by concrete actions on the ground.

This process of conducting this research has raised awareness of disability issues, as well as facilitating the first ever stakeholder workshop on disability in Rwanda,

funded by the Disability KaR programme and organised by VSO. It is hoped that this report will also be of use to the government, donors, international and local NGOs and DPOs, to take forward work on disability.

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Annexe 1: Terms of reference for the study

Objective
The first objective of this assignment is to give DFID Rwanda and the Government of Rwanda access to information and recommendations that can guide policy and implementation practice to achieve higher levels of social inclusion for disabled people.

In particular, the information gathered will be used to help formulate social protection policy in Rwanda.

The second objective is for this information to be used as part of a three-country study to help DFID develop policies and processes to mainstream disability.

Scope of work
Rwanda has been selected, following consultation, as one of the three countries for the DFID Action Research. In order to be responsive to the particular needs of Rwanda, the following country specific-research objectives have been framed:

- to review and examine the current situation of disabled people and the status of disability issues in Rwanda, including:
  - the scale and nature of disability in Rwanda, drawing on existing quantitative and qualitative data (from the Institute of Statistics)
  - legislative and policy commitments of the Government of Rwanda on disability issues (including within the PRSP and in key sector policies such as education and health)
  - identifying any existing or planned social protection transfers to disabled people from all sources
  - examining the main providers of support for disabled people and the organisational arrangements that make this possible
  - identifying some of the causes or reasons for disability, and whether any of these are addressable and what manner of policy or implementation changes would be required to achieve this.
  - identifying and examining channels for advocacy on behalf of disabled populations identified and examined for their effectiveness
- to analyse the meaning of social inclusion for disabled people in Rwanda and describe what is known of their aspirations for inclusion
  to map current disability-focused activities in Rwanda (government, multi-lateral and bi-lateral development agencies, civil society organisations) and identify examples of best practice
- to analyse the opportunities and constraints facing the Government of Rwanda to take forward work on disability, particularly within new policy on social protection and in the key sectors of health and education
- to identify potential partners to assist the Government of Rwanda with future policy and programme development on social protection relating to disability.

Methodology
The Disability Policy Officer of the DFID Disability KaR Programme, Philippa Thomas, will be the principal researcher. The research will be carried out in the UK and in Rwanda. The Disability Policy Officer will be assisted in the in-country research by a local disabled researcher.

The assistant researcher will be able to assist the Disability Policy Officer in the following areas:

- identifying interviewees, especially from local civil society organisations
- facilitating meetings
- interpreting interviews (Kinyarwanda, French and English)
- providing local contextualisation and understanding.

The Disability Policy Officer will be responsible for:
- communicating with DFID Rwanda and ensuring that all relevant DFID HQ staff are kept fully informed
- identifying and reviewing key documents
- identifying the local research assistant, developing their workplan and managing them
- conducting in-country research, involving reviewing documents and carrying out semi-structured interviews with key DFID personnel and Rwandan stakeholders, and programme/project field visits
- preparing the Rwanda country report
- providing technical support to country offices in identifying means to take recommendations forward.

Specific activities

- Organising a seminar for DFID Rwanda and invited guests to present preliminary findings
- Carrying out semi-structured interviews with DFID Rwanda staff
- Conducting interviews with other donors, faith-based organisations, NGOs, the Government of Rwanda, and disabled people's organisations
- Facilitating some meetings with key informants (such as government staff and DFID partners)
- Using a desk and telephone for part of the in-country research
- Ensuring access to information available locally
- Making all logistical arrangements (such as travel to and within the country and accommodation) for in-country visits.

Outputs
- Compiling a country report containing:
  - a summary of the current situation of disabled people in the country and initiatives addressing disability
  - an analysis of opportunities and constraints to take forward work on disability within wider work on social protection and in the key sectors of health and education
  - clear indications of what a country office such as Rwanda should expect to see in the PRSP and the MTEF
  - examples of best practice and a list of potential partners and key country contacts
  - recommendations for DFID Rwanda to share with the Government of Rwanda
- Identification of a network of support partners for DFID Rwanda and the Government of Rwanda
- Case study material to inform DFID's planned policy on social exclusion and strategy for inclusive development.

Timing

Desk studies of secondary sources will be made in advance of the visit to Rwanda. The visit to Rwanda will be for two weeks from January 10 2005. The seminar will

take place one day before departure. The report will be presented in draft form to the Senior Social Development Adviser, DFID Rwanda within one month of the completed visit.

Activity	Completion date
Agree final terms of reference	End November 2004
Identify local researcher	End November 2004
Complete UK-based desk research (up to 10 person days) and in-country research including preliminary report (up to 21 person days)	End January 2005
Complete country report	End February 2005

Reporting
While in Rwanda, the Disability Policy Officer will collaborate closely with the Senior Social Development Adviser.

The Disability Policy Officer is based within DFID's Central Research Department but links primarily with the Diversity Adviser, the Gender and Human Rights Adviser and the newly established Exclusion, Rights and Justice (ERJ) team within the Policy Division at DFID HQ.

Background

The Disability Policy Project is one of several components of the DFID Disability Knowledge and Research (KaR) Programme.The goal of the Disability Policy Project is to assist DFID to develop policies and processes to mainstream disability, and to ensure that the Disability KaR's knowledge and research outputs are responsive to DFID's needs and effectively communicated to DFID.

The first major output of the Disability Policy Project was a mapping study of DFID's current work on disability, *DFID and Disability: A mapping of the Department for International Development and disability issues* (Thomas 2004).[3]

The disability mapping report aimed to provide a snapshot of what DFID was doing to address disability issues. It identified the following key issues:

- DFID has not mainstreamed disability, but there is a solid bedrock of disability-specific activities being carried out, largely via NGOs and CSOs.

- DFID's work on disability is largely hidden, and often DFID staff and country offices are unaware of disability-focused activities being carried out by NGOs and CSOs.

- While DFID staff broadly recognise the links between poverty and disability, they do not necessarily see disability as an essential part of their work on poverty reduction and the achievement of the Millennium Development Goals.

- DFID staff need more information on disability – in particular, practical tools and examples of best practice, to enable them to implement the twin-track approach

[3] Full text of the report can be downloaded from the Disability KaR website at: www.disabilitykar.net

outlined in DFID's issues paper *Disability, Poverty and Development* (DFID 2000).

Mainstreaming disability in development (MDD) action research

It is proposed to build on and extend the initial DFID mapping by conducting three pieces of action research on disability mainstreaming in three countries where DFID works. The generic research objectives for the study are:

- to explore how three DFID country offices see the issue of disability in relation to their work on poverty reduction, social exclusion and the Millennium Development Goals (MDGs)
- to explore how the inclusion of disability issues can contribute to the reduction of poverty and social exclusion and the achievement of the MDGs
- to map what three DFID country offices are currently doing to address disability issues and identify examples of best practice[4]
- to identify opportunities and potential partners for each DFID country office to take forward work on disability – particularly in relation to key sectors such as health and education
- to inform the development of a planned DFID policy on exclusion and the Exclusion, Rights and Justice (ERJ) team's workstream on inclusive development

[4] The identification of best practice could extend beyond the work of the DFID country office to include government, development agencies (bi-lateral and multi-lateral) and non-governmental and civil society organisations

Annexe 2: Schedule of meetings

Week 1

Day and time		Organisation	Contact	Tel no
Mon Jan 10	08h00-12h00	DFID and briefing		
	13h00-15h00	Ministry of Education, Special Needs Division	Mary Kobusingye	0250 8519705/ 582445
	16h00-17h00	FERHANDIS	Dominique Bizimana	0250 8618220
Tues Jan 11	08h00-09h00	Social Protection Officer	Benjamin Ndahirwa	--
	09h00-10h00	MINALOC	Straton Nsanzabaganywa, Director of Social Security and Protection of Vulnerable Groups	0250 8510494
	10h00-11h00	FACHR	Gastone Rusiha	0250 8302982
	11h00-12h00	Deputy Ombudsman	Bernardin Ndashimiye	0250 8306645
Weds Jan 12	08h00-09h00	Rwanda Association for Disabled Women	Pelagie Muhorakeye	--
	09h30-10h30	MIGEPROF	Anne Gahongayire (SG)	--
	13h00-14h00	AGHR	Zacharie Nkundiye	--
Thurs Jan 13	08h00-09h00	FARG	JM Karekezi	0250 8307340
	9:30-10h:30	MJOLP	Emmanuel Gatera Rudasingwa	0250 8517332
	11h00-12h00	Rwanda Commission For Human Rights	Denis Uwimana	0250 8302013
	13h00-14h00	Handicap International	Sylvain	--
	14h30-15h30	CBM	Clementine Kilibanzayire	0250 8452512
Fri Jan 14	08h00-09h00	National Electoral Commission	Speciose Nyiraneza	--
	11h00-12h00	Rwanda National of Deaf	François Twahirwa	--
	12h00-13h00	MIGEPROF	Anne Gahongayire	0250 8305501
	14h30-15h30	Rwanda Union of the Blind (MUHIMA)	Patrick Suubi	--
	16h00-17h00	Blind People's Association	Wellars Kazamarande	0250 8756145

Week 2

Day and time		Organisation	Contact	Tel no
Mon Jan 17	08h00-09h00	National Electoral Commission	Protais Rumanzi	0250 583995
	09h30-10h30	UNICEF	Jose Bergua	--
	11h00-12h00	Youth MP	Francis Kaboneka	0250 8303650
	14h30-15h30	CESTRAL (trade union)	Eric Manzi	--
	17H00-18H00	MINISANTE	Velentine Kilibanzayire	--
Tues Jan 18	08h00-09h00	Save the Children UK	Phennny Kakama	--
	09h30-10h30	National Youth Council	Giovanni Renzaho MP	--
	14h30-15h30	Mental Facility Ndera	--	--
Weds Jan 19	0900-17h00	VSO workshop	--	--
	17h30-18h00	House of Deputies	U Innocent Twagirayez MP	--
Thurs Jan 20		Gisenyi Province, focus group 1	Annicet Nkunzimana	0250 8868429
Fri Jan 21		Ruhengeri Province, focus group 2	Epaphrodite Nsengimana, Vice-Mayor	--
			Jean de Dieu	0250 8476411

Week 3

Day and time		Organisation	Contact	Tel no
	09h30-11h30	Gitarama Province	Gatagara – Lies Vandenbossche, volunteer social worker	0250 8772080
Tues Jan 25	10h00-12h00	Kigali Ngali Province	Personal Interviews	--
Weds Jan 26	08h00-09h00	Demobilisation Commission	Stephen Karengera	--
	15h00-17h00	DFID Seminar		--

Annexe 3: Interview questions

Name	
Position and organisation	
Contact details	

A: Disability and your work

1) Could you give me a brief summary of what your job involves?

2) How relevant is disability is to the overall goals and work of your organisation?

3) Are you aware of any policies or statements produced by your organisation on disability issues?

4) Do you consider disability to be a relevant issue in your work? If no, why not? If yes, why?

5) How have you sought to address disability issues? Please give examples.

6) Do you know of any specific initiatives, programmes or projects specifically targeting disabled people that your organisation is supporting?

7) What difficulties have you faced in trying to address disability issues?

8) What areas would you like more help with?

B: Disability and development in Rwanda

What do you know about the situation of people with disabilities in Rwanda (for example, scale/prevalence of disability, causes of disability, socio-economic situation of people with disabilities and so on)?

10) Are you aware of any legislative or policy commitment on the part of the Government of Rwanda towards people with disabilities?

Outside of your own organisation, are you aware of any disability-specific programmes or activities being delivered in Rwanda (for example, government, international and local NGO activities)?

11) Are there any disability programmes / activities in Rwanda that you consider examples of best practice? What are they? Why have you chosen them?

12) What progress has been made in addressing the needs of people with disabilities in Rwanda?

13) What more needs to be done in addressing the needs of people with disabilities in Rwanda?

14) What is, or should be, the role of the government, multi and bi-lateral donors, international and local NGOs, and wider civil society in addressing the needs of people with disabilities in Rwanda?

15) What do you see as the main opportunities and constraints for taking forward work on disability issues in Rwanda?

16) What does ‘mainstreaming disability’ mean to you?

C: Knowledge about disability

17) What do you understand by the term ‘disability’?

18) In Rwanda, what is the most useful way of looking at disability? For example, is it a medical issue, a poverty issue or a human rights issue?

D: Conclusion

20) Can you recommend anyone else I should contact?

Annexe 4: Focus group – Gisenyi

1. Woman (35 years), not married, polio paralysed both legs
2. Woman (27 years), not married, polio two legs
3. Woman (26 years), not married, spinal cord from accident for eight years
4. Woman (30 years), not married, polio one leg
5. Man (29 years), married lost arm in war in 1994
6. Woman (30 years), not married, polio
7. Woman (26 years), not married, polio
8. Man (35 years), not married, polio
9. Man (36 years), married, four children, polio
10. Man (27 years), not married, polio
11. Man (23), not married, lost two arms in the war
12. Man (59 years), married, four children, blind following a beating in the 1963 war
13. Man (34 years), married, polio one leg
14. Man (48 years), married with five children, amputee from car accident
15. Man (34 years), not married, polio two legs
16. Woman (20 years), not married, polio one leg
17. Woman (38 years), not married, polio one leg
18. Man (65 years), married with six children, amputee from car accident 23 years ago
19. Man (50 years), married, two children, deaf for 12 years
20. Woman (42 years), widow, two children, one leg problem since a car accident in 1997
21. Woman (20 years), not married, mentally handicapped
22. Man (34 years), married, three children, amputee from since 1993 in war
23. Man (36 years), married, four children, amputee, one leg car accident since 1979
24. Man (21 years), not married, polio one leg
25. Woman (44 years), married, five children, centre founder
26. Man (47 years), married, nine children, paralysed one arm since 1982
27. Man (46 years), widower, three children, spinal cord injury after a beating in the war.

Ruhengeri

1. Woman (30 years), not married, paralysed one leg
2. Woman (33 years), married, two children, polio one leg
3. Woman (42 years), not married, three children, paralysed one leg
4. Man (40 years), married, three children, polio two legs
5. Man (42), married, six children, amputee one leg
6. Man (42), married, six children, deaf since birth
7. Man (33 years), married, three children, paralysed one leg
8. Man (35 years), married, four children, paralysed one leg
9. Man (39 years), married four children, paralysed one leg
10. Man (25 years), not married, paralysed one leg
11. Man (32 years), married, three children, paralysed one leg
12. Man (40 years), married, five children, polio one leg
13. Man (24 years), not married, polio one leg
14. Man (22 years), not married, polio one leg
15. Man (29 years), married, two children, polio one leg
16. Woman (33 years), not married, polio one leg

17. Man (30 years), married, two children, polio one leg
18. Man (33), not married, two children polio one leg
19. Man (45 years), married, seven children, amputee one arm
20. Man (38 years), married, two children, amputee one leg

Disabled people's focus group questions

1. What is the attitude of Rwandan's towards disabled people?
2. Are some kinds of disability more accepted than others?
3. What are main problems that you face because you are disabled?
4. How easy do you find it to get:
   - medical care?
   - education?
   - find work and earn a living ?
5. Do you participate fully in activities in your community – for example, participating in meetings, celebrations, development activities
6. Have you taken part in any government programmes, such as the HIMO programme or Mutuelle de santé
7. Did you vote in the last elections?
   Do you know about the disabled MP?
   Do you know about any government policy or legislation on disability?
8. Are your local authorities interested in disability?
   Have the local authorities done anything to support disabled people?
9. What do you know about HIV/AIDS?
   Is HIV/AIDS a problem for disabled people?
10. What does disability mean for you?

Annexe 5: Organisations working in disability

Project RBC CARAES Ndera (Centre de Jour Humura)
Local NGO
PO Box 423 Kigali, Ndera, Kabuga Town Tel: 0250 520941/8465681 Email: orestegasana@yahoo.fr
• Vocational training and education for mental handicapped children

Veteran Development Association (VDA)
Local NGO/DPO
c/o MINALOC, PO Box 3445, Kigali Tel: 0250 8437961
• Advocacy • Vocational training

Rwanda Union of the Blind (RUB)
Local NGO
PO Box 1527 Kigali, Muhima Tel: 0250 576097/8856671 Email: kdonatilla@yahoo.com
• Advocacy • Self-help groups • Vocational training

RBC Inkurunziza
Local NGO
PO Box 105 Kigali, Gikondo, Kigali City Tel: 0250 519219/516445 Email: cbr-kigali@hotmail.com
• Eye care • Rehabilitation • Training for physiotherapists

Association des Amis de l' Abbé Fraipont (AAF)
Local NGO
Tel: 0250 8434085 Email: intwagira@yahoo.fr
• Social reintegration • Self-help groups

Association Rwandaise de Lutte Contre le VIH/SIDA (ARPH/SIDA)
Local NGO
PO Box 592, Kigali Tel: 0250 886434 Email: arphlsida@yahoo.com
• Sensitisation • Self-help groups

Association des Techniciens Orthopediste du Rwanda (ATOR)
Local NGO/self-help group
PO Box 4462, Kigali, Nyamirambo Emile Mudaheranwa

• Prothesis production

Handicap International
International NGO
PO Box 747, Kimihurura, Kigali Tel: 0250 584206/8300750 Email: direction@hi.org.rw/readaptation@hi.org.rw Déo Butera
• Rehabilitation • Advocacy • Vocational training

Centre des Jeunes Sourds Muets (CJSM)
Local NGO
PO Box 65, Butare Tel: 0250 530958/8527019 Email: rutsindalex@yahoo.fr
• Education

Special Needs Education (MINEDUC)
Government department
PO Box 622, Kigali Kacyiru Tel: 0250 582445 Email: marryk7200@yahoo.co.uk
• Placement of children with disabilities • Teacher training in special needs education

Department of Mental Health (KHI)
Government department
CARAES Ndera Kaabuga Town Tel: 0250 513596
• Training for mental health professionals

Umutara Handicapped Association (UBUMWE)
Self-help group
Email: amstrong_eugene@yahoo.fr
• Income generation

Mulindi Japan One Love Project
Local NGO
Tel: 0250 513154/5817331/85117332 Email: onelove@rwanda1.com
• Orthopaedic appliance production • Vocational training

Foundation of Disabled People in Rwanda (FDPR-URUFATIRO)
Self-help group
0250 8647391/8752996 Email: badegesam@yahoo.fr
• Advocacy • Income generation

AMIZERO des Aveugles
Self-help group
PO Box 1770, Kigali Tel: 0250 8756145

• Vocational training • Income generation

CRH GAHINI
Local NGO
PO Box 22, Kigali Tel: 0250 567786/8623864
• Rehabilitation • Orthopaedic appliance distribution • Inclusive education • Community-based rehabilitation

Federation of Associations and Centres For Disabled People of Rwanda (FACHR)
Semi-autonomous government body
PO Box 3445, Kigali Tel: 0250 8302982/8836180/8686221 Email: fachr@yahoo.fr Rusiha Gastone
• National coordinating and advisory body • Advocacy

Neuropsychiatry hospital of Ndera
Local NGO hospital
PO Box 423, Kigali Tel: 0250 8307932 Email: cnkubili@yahoo.fr Charles Nkubiri
• Mental health assessment

Association of University Disabled Students of Rwanda (AHUR)
Self-help group
Tel: 0250 8486508 Email: ahuunr@yahoo.fr
• Advocacy • Self-help groups • Education

MINISANTE/Rehabilitation of People with Disabilitie Planning Department
GoV
Tel: 0250 502909/8468394 Email: kilivalentin@yahoo.fr
• Activity coordination and fighting against blindness • Statistical data • Database

HVP Gatagara
Local NGO
PO Box1134 Kigali Tel: 0250 8309666/8302054 Email: celengend@yahoo.fr frnkkverh@yahoo.fr Contact: Brother Célestin Ngendahimana
• Special and inclusive education • Social reintegration

• Rehabilitation • Orthopaedic surgery

American Embassy Democracy and Human Rights Fund
US government department
PO Box 28 Kigali, American Embassy Tel: 0250 8307268 Email: McIntoshc@state.gov Contact: Carey McIntosh
• Provides funding for small projects and advocacy

Féderation Rwandaise Handisport (FERHANDIS)
Local NGO
Tel: 0250 8618220 Email: sporthand@yahoo.fr bizidom@yahoo.fr Contact: Dominique Bizimana
• Sport for disabled people • Advocacy • Social integration

Rwanda National Association of the Deaf
Self-help group
PO Box 5188, Kigali Tel: 0250 8425417 Email: rnad2003@hotmail.com
• Sensitisation • Advocacy • Vocational training

Association Géneral des Handicapés au Rwanda (AGHR)
Local NGO/self-help group
Contact: Zacharie Nkundiye PO Box 4211 Kigali, Gitega Email: aghrw@yahoo.fr
• Social and economic reintegration • Self-help groups • Sensitisation

MINALOC/Social Protection Unit/Social Security and Protection of Vulnerable Group Direction
GoV
PO Box 3445, Kigali Tel: 0250 514410/8510494 Email: nsanzastrat@yahoo.fr
• Policy making • Funding

Rwanda Demobilisation and Reintegration Commission
Semi-government autonomous
[Contact: Faustin Rwigema Tel: 0250 8303766 Email: demob@rwanda1.com
• Demobilising and reintegrating veterans • Lump-sum payments to disabled veterans

• Free medical treatment

National Assistance Fund for Needy Victims of Genocide and Massacres in Rwanda (FARG)
Semi-government autonomous
PO Box 4256, Kigali Email: farg@rwandatel1.rwanda1.com Contact: Jean Marie Karekezi, Executive Secretary
• Education • Housing • Medical care

Christian Blind Mission (CBM)
International NGO (German)
[Contacts:] Rudolf Czikland, Clementine Kilibanzayire Tel: 0250 8452512
• Rehabilitation • Eye care • Community-based rehabilitation

Amizero Centre
Local NGO
Kigali Tel: 0250 8410349 [Contact: Jamuel Muhayimana
• Rehabilitation • Mental health

CHUK and CHUB
Government hospitals
CHUK (Kigali University Hospital) CHUB (Butare University Hospital)
• Rehabilitation • Surgery

Annexe 6: Sample disability classification system – Cambodia

The definitions in the following table were developed and agreed following a long process of discussions among all stakeholders, and represent a significant breakthrough in coordinating future data on disability in Cambodia. They are easy to use and ideal for use in the community enabling local people to describe the functional problems of disabled people in their communities. (It may serve as a model for a single classification system to be established in Rwanda.)

Type of disability	Definition	Disabilities
Seeing difficulties	Person who is short sighted, low vision or could not see any objects	Blind one eye/both eye, optic nerve damage, dislocated eyes (could not see), ptosis (eyes with weak muscles), corneal scar, trichinosis, hypohema, retinitis, retinitipigmentosa
Hearing difficulties	Person who has a hearing impairment (at birth or due to injury or disease) or due to the ageing process	Deaf, earless person, ear without ear drum(s), perforation of ear drum(s)
Speaking difficulties	Person who has difficulty in saying words and can not say clearly enough or at all, or not enough to be understood by other people	Speaking impaired person, cleft lip and cleft palate, big tongue, mute, slurred (speech not clear), stick teeth
Moving difficulties	Person who has physical difficulty in moving from one place to another or in moving a part of hi/her body, or who cannot move at all	Amputee arm(s)/leg(s), polio, muscular dystrophy, contracture, tight muscles, Cerebral Palsy, club foot/feet, bowed legs, congenital defect, dwarf, paraplegia, hemiplegia, quadriplegia, paralysis, spinal cord curve (kyphosis/ lordosis), dislocated hip, broken bone (fracture), juvenile arthritis, osteoarthritis, TB bone deformity, osteoporosis, scoliosis
Feeling difficulties	Person who has lost sensation or does not feel anything while touching objects	Third degree of leprosy (Hansen's disease), person who has severe beriberi (numbness) of the hands or legs, parahemiplegia, kwashiorkor
Psychological difficulties (strange behaviour)	Person who changed behaviour so much that now he/she behaves like a different person, it happens regularly and they have difficulty in feeling, thinking and/or behaviour	Schizophrenia, paranoia, neurosis, mania, stress, anxiety, depression, psychosis
Learning difficulties	Person who has low memory, could not remember or do things like other people of the same age	Intellectual disability, Down's syndrome, slow learner, cerebral palsy, autism
People who have fits	Person who often has convulsions and foams at the mouth	Epilepsy, hypoglycaemia, hyperglycaemia
Other	Person who has restrictions in physical and social functioning	Disfigurement/deformity, chronic illness, dwarfs, midgets, hydrocephalus, HIV/AIDS-related conditions, severe keloid

Source: Mackinlay (2004)