World Vision

# all things being equal

## perspectives on disability and development

all things being equal: perspectives on disability and development Autumn 2001

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# foreword

## setting the international scene – rights, rhetoric, reality

**Dr Bengt Lindqvist**

*UN Special Rapporteur on Disability*

*'We know that persons with disabilities frequently live in deplorable conditions, and face physical and social barriers which prevent their integration and full participation in the community.*

*Despite the adoption by the UN General Assembly of the World Programme of Action concerning Disabled People, and the adoption in 1993 of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, it is clear that a great deal needs to be done'*

**Mary Robinson,**
UN High Commissioner for Human Rights, *'Let the World Know' Seminar (2000)*

Throughout the centuries we have designed and constructed our societies as if persons with disabilities did not exist, as if all human beings can see, hear, walk about, understand and react quickly and adequately to signals from the world around them. This inability to take the needs of all citizens into account in the development of society is the main reason for the isolation and exclusion of persons with disabilities, which we can observe in different forms and to different degrees all over the world.

There is a readiness within the United Nations to take the mainstreaming of disability seriously, both as an issue of social development and increasingly as a violation of human rights. Most recently, the UN Commission on Human Rights included the disability dimension in monitoring the general treaties on human rights. The resolution aimed to strengthen the capacity of NGOs, treaty bodies and states – each important actors in promoting the rights of people with disabilities.

Yet progress in taking up this opportunity has been slow. There is a still a need for mutual learning. Disability leaders need to learn how to communicate their experiences to the human rights monitoring bodies. Human rights experts need to learn more about how various *'obstacles prevent persons with disabilities from exercising their rights and freedoms and make it difficult for them to participate fully in the activities of their societies'* (Standard Rules, para 15).[1]

It was with this in mind that my office convened **'Let the World Know' (2000)**, a seminar designed to develop capacity and competence within all the parties concerned. Not until reports about the occurring gross violations of the human rights of disabled persons start to reach the appropriate entities within the UN system will there be a change in the basic attitudes towards this area of human rights within governments and political parties around the world.

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[1] UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993)

**'Let the World Know'** identified five separate areas that must be monitored for human rights abuses:

- Documenting and reporting **individual cases of abuse** raises awareness and support and makes it difficult for governments to falsely claim that their citizens' rights are respected.
- The laws of a country must be reviewed and compared to international standards to make clear what impact **state laws and policies** are having on the rights of their citizens.
- Regardless of what a law says, what matters is how it is interpreted. An international web site could compare **legal cases and decisions** against international human rights standards.
- To assess the impact of **government programmes, services and practices** special reporting manuals could be made available to disability rights groups. Completed manuals sent to the UN could be used to measure how well specific governments are complying with international standards and human rights guarantees.
- The **media** has tremendous impact. A 'Disability Rights Media Watch' could be responsible for monitoring media across the world for reports of human rights abuses. Reports would then be made available internationally to all disability rights groups, the UN and government agencies.

> There is a readiness within the United Nations to take the mainstreaming of disability seriously

These ideas must now be put into action and refined. This will lead to strong and effective ways of measuring our progress and promoting respect for the human rights of persons with disabilities. It is the next obvious step in moving from rights on paper to rights in reality.

At the end of the seminar, in recognition of our work, I planted an acorn as a reminder to us all that it is 'from little acorns that great oaks grow'. Marcia Rioux, the Rapporteur to the seminar commented that *'the roots of justice are secured in honouring the human rights of people with disabilities'*. Underlying World Vision's discussion paper is the desire to work alongside and address some of the injustices faced by those who are most vulnerable. I welcome their desire to contribute towards this common goal.

# introduction

**Helen Foakes &**
**Helen Ryman**

*Policy,*
*World Vision UK*

Estimates suggest that there are as many as 600 million people with disabilities world wide – a staggering one in ten of the population.[1] Yet, despite the numbers, disabled children and adults can often seem almost invisible – set apart as different or seen as a 'burden' and frequently excluded from the everyday life of the society they belong to. At worst, they are hidden away in shame or placed in specialist institutions and even where this does not happen, disabled people are rarely afforded the same opportunities as others within their family or community. Whether in terms of education, employment or decision-making, disability is frequently seen by others to pose many problems. However, as the debate around disabled people's rights intensifies, recognition is growing that many of these so-called 'problems' do not arise from the physical, mental or sensory impairment of an individual but rather from the social barriers that surround them through prejudice, superstition or apathy.

Such meaningful participation by disabled people can only be ensured if the social barriers encountered are broken down

The fact that most development agencies have traditionally seen disability as a specialist issue is also significant. The belief that disabled children and adults are best helped through separate, specialist provision has focused attention onto particular needs. Yet, in doing so, this approach has failed to recognise the totality of their rights, as expressed in various UN articles and activities.[2] Rights which, according to the UN Standard Rules,[3] include not only having access to appropriate care and protection but also being able to participate in everyday activities in the community and to be decision makers. If all of these rights are to be realised, a very different approach is needed – one that sees disabled people as active participants rather then helpless beneficiaries and that seeks to include them at every stage of the development process.

Such meaningful participation by disabled people can only be ensured if the social barriers encountered are broken down. As a starting point for this, awareness raising at every level, from the family and the wider community to national government, is of vital importance. World Vision is an organisation committed to working alongside the most vulnerable people and recognises the need to take on this challenge. Disabled children and adults are often the most marginalised within the development process – World Vision estimates that up to 20 per cent of people living in poor communities are disabled – and only by acknowledging and promoting their equal rights can this be changed. World Vision also knows from experience that the greater the involvement of the whole community, the more potential there is for positive and lasting change. Therefore, ensuring the inclusion of disabled people in mainstream development programmes is actually a crucial part of successful and sustainable community development.

Recognising the need to raise awareness on a number of different levels, this discussion paper is intended for a wide audience and

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[1] United Nations, *'Fundamental rights of disabled persons consistently violated around the world, Commission for Social Development told'*, Press Release SOC/4528, February 2000

[2] Most recently, in addition to the Universal Declaration of Human Rights and the Convention on the Rights of the Child, the **Long-term strategy to implement the World Programme of Action concerning Disabled Persons to the Year 2000** (1992), and the **Standard Rules on the Equalisation of Opportunities for Persons with Disabilities** (1993). International conferences such as the **World Conference on Special Needs Education: Access and Quality**, Salamanca (1994) and the **World Summit for Social Development**, Copenhagen (1995) have also clarified the rights and needs of people with disabilities.

[3] UN, (1993) Standard Rules on the Equalisation of Opportunities for Persons with Disabilities

focuses specifically on the issues surrounding disability and development. The articles draw on experiences of disability from around the world and are intended to inform and stimulate current debate and practice.

The first article, by Jane Betts and Jonathan Flower (World Vision UK), looks at the quality of development agency programming. Drawing on their experience at World Vision, they also include examples of innovative practice by other organisations. The authors identify barriers to the inclusion of disabled people and demonstrate that creating a 'level playing field' is both necessary and achievable. The conclusion highlights the need for all those involved in development programming to create an 'enabling' rather than 'disabling' environment.

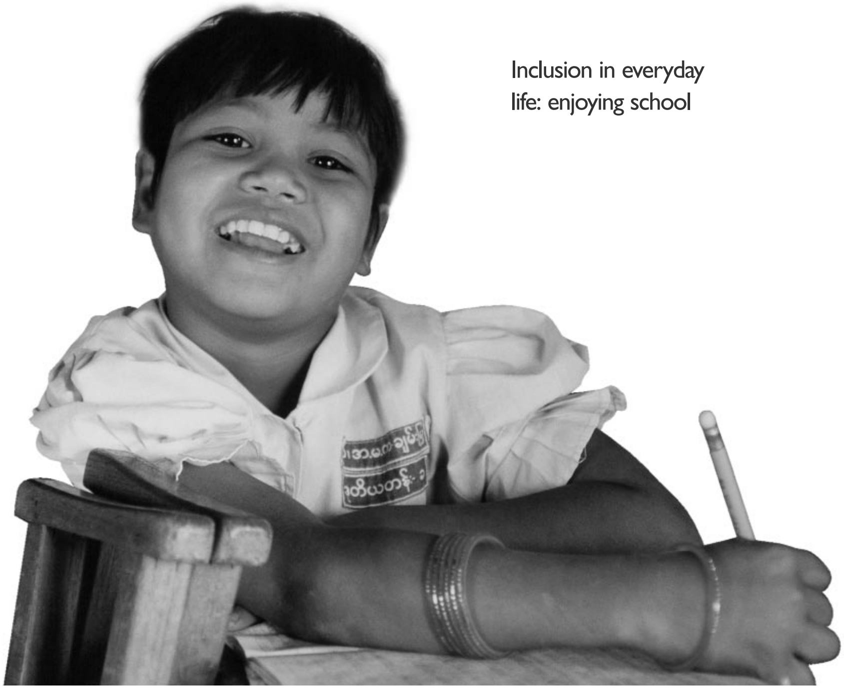
Following on, Rachel Hurst (Disability Awareness in Action) and Gerison Lansdown (Rights for Disabled Children) tackle the question of what human rights mean for children and adults living with disability on a daily basis. They analyse the potential protection offered to disabled children by the UN Convention on the Rights of the Child and, in contrast, give examples of the disabling effect the denial of rights has had upon young people. Hurst and Lansdown urge vision, commitment and a willingness to listen to disabled children and their families, and propose a ten-point action plan towards promoting the rights of disabled children.

The next article comes from The National Union of Disabled Persons of Uganda (NUDIPU), an organisation with fourteen years experience of campaigning for the rights of disabled people in Uganda. Benon Ndaziboneye explores NUDIPU's current campaigns around education, assistive devices and micro-finance, and provides concrete examples of how success can be achieved by creating a unified voice for people with disabilities.

From the international perspective, Professor Colin Barnes (Centre for Disability Studies, Leeds University) introduces the thinking behind the latest draft World Health Organisation (WHO) recommendations from the recent 'Rethinking Care' conference held in Norway. Recognising the inadequacy of conventional notions of medicine and rehabilitation, these international recommendations call for a more holistic approach from state actors, and detail the actions necessary to ensure disabled people's rights in the economic, political, cultural and social spheres.

Disabled children and adults are often the most marginalised within the development process

Focusing back at local level, Mosharraf Hossain (Action on Disability and Development, Bangladesh) draws on his experience as a programme manager to give a practical insight into what can be achieved when disabled people organise together to promote their rights. Hossain details lessons



Inclusion in everyday life: enjoying school learnt through disabled people's self-organisation, such as the need for democratic, transparent and participatory systems, and explores the positive outcomes of taking a rights-based approach.

Finally, the paper closes with a thoughtful piece by Hugh Nelson (L'Arche community) and an anonymous poet who present their spiritual experiences and bring an alternative dimension to the debate.

What is striking about all these contributions, incorporating many different angles and experiences as they do, is their unified voice and urgent tone. They all give a clear message that awareness raising must go hand in hand with action. A challenge is therefore laid down to each and every individual and organisation to break down the visible and invisible barriers that violate human rights and deny the true inclusion of people with disabilities in everyday life.

Just one example of promoting equality: involving society in integrating disabled people, physical assistance for mine victims, mines awareness talks to local communities and campaigning against landmines at international level

# towards a level playing field

## a call for action to make development programmes more inclusive

**Jane Betts & Jonathan Flower**

*Programme Development, World Vision UK*

### introduction

According to the Department for International Development (DFID) and the World Bank, as many as one in five of the world's poorest people are disabled.[1] Most are stuck in a spiral of deprivation in which powerlessness, vulnerability, physical weakness and isolation are reinforced and keep them in abject poverty.[2] The aim of this paper is to demonstrate the need for 'a level playing field' in order that disabled people can participate fully in the development process, with particular emphasis on the role of international non-governmental organisations (INGOs).

### barriers to inclusion

The general perception of disability is changing. A handful of NGOs have started to take this on as a human rights issue, having embraced the conclusion that every person has an equal right to participate fully in society. Others still address disability as a narrow health issue to be dealt with by professionals, or in terms of an individual and their impairments. What is needed however, is a consolidated effort to break down the disabling barriers put up by society itself. Only then can we ensure that people with disabilities in the world's poorest communities have an equal opportunity to reach their potential.

In a recent development project evaluation in Burma[3], community members in six townships (both disabled and not) listed the problems and constraints faced by disabled people in their communities.

**The issues raised were** (in priority order):

1. Insufficient income to maintain a sustainable livelihood
2. Mobility/transport constraints
3. Limited access to education
4. Social exclusion
5. Constraints due to impairments
6. Lack of care and family support
7. Inability to meet primary needs and poor living conditions
8. Not treated as equals by peers
9. Inability to turn a skill into a successful business

Poor health, difficulties in carrying out activities for daily living, depression and communication difficulties were mentioned, but only by two or three of the 17 groups that participated. These findings are a potent illustration of how the main needs of disabled people differ little from the rest of society. For example, these were poor communities some distance from the main work opportunities, so transport was difficult for all, but for some, disability magnified the issue. The most important disability-related issue was social exclusion, and disabled people listed a variety of barriers that their communities put up that prevented or impeded their inclusion. Impairment related constraints were rated fifth on their list of priorities, and health hardly featured at all.

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[1] Elwan, (1999) *Poverty and Disability; a background paper for the World Bank Development Report*, Washington, Department for International Development, (2000) Disability, poverty and development, DFID: London

[2] Chambers R, (1983) *Rural Development: Putting the Last First*, Longman Scientific and Technical: Harlow

[3] Flower J, (2001) *Mid-term evaluation of CBR programme in Mandalay and Rangoon*, Report written for World Vision and DFID, UK (unpublished)

So what kind of barriers to inclusion do disabled people face? Those that occur within communities and the organisational thinking of INGOs include the following:

- **attitudes and prejudice** are woven into cultural practices at both community and organisational levels. These sometimes take the form of ignorance, which may stem from a misunderstanding of the issues or simply never having considered them, apathy, or even denial. It is not unusual for an organisation to be unwilling to face up to the reality that it is excluding a particular group of people and so to proceed as if the issue does not really exist. Additionally, every society has myths, traditions, superstitions and beliefs about disability, most if not all of which are factually wrong. Two thousand years ago people asked: *'Who sinned, this man or his parents, that he was born blind?'*[4] Jesus dismissed the idea that blindness was anybody's fault. The consequences of such beliefs place disabled people in a negative light, and mean they are likely to be discriminated against or even hidden away in homes or institutions.

- **overload and cost** are often cited as reasons not to include disabled people. Whether in development programmes, schools or human resources departments, inclusion is often seen as 'just another time consuming, expensive burden'. However, the evidence is often to the contrary. Including disabled people in development programmes can help I/NGOs tackle the obstacles of working with the poorest people; many countries have found that inclusive education is more cost-effective than special education[5]; a population that works is less of a burden on families and societies than one that does not, and all organisations would do well to tap into the broadest spectrum of creative talent that is available to them.

- **sustainability** is sometimes thought to be put in jeopardy by the inclusion of disabled people and other 'special groups'. However, AusAID's guidelines counter this by stating that: *'sustainable development can only be achieved with the active participation of all members of the community'.*[6]

- **inclusion versus a disability emphasis** are two concepts that seem contradictory at first glance. Recently the BBC disbanded its Disability Unit in order to laudably include disability in all sectors. However, at the BBC Sports Personality of the Year Awards (2000) in London, with para-Olympian and London Marathon winner, Tanni Grey-Thompson one of the nominees, the newly inclusive BBC had created a totally uninclusive set. Of all the winners, only Tanni was unable to get on to the stage to collect her prize!

  The same issue is being faced by the growing number of people who are lobbying for a UN Convention on the Rights of People with Disabilities. At a recent Conference on Disability Rights held in London, Macline Twimukye, executive director of the National Union of Disabled Persons of Uganda, and many others argued that the existing conventions,[7] which should guarantee the rights of disabled people, are simply not doing so. Other marginalised groups have had this situation partially addressed by the adoption of specific treaties. States that ratify these treaties have to regularly report on the progress they are making.[8] By giving the case of disabled people similar attention their rights would begin to be upheld (Twimukye, Disability Rights: A Global Concern Conference, June 2001).

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[4] *The Holy Bible* New International Version (1998), Hodder and Stoughton: London, John Chapter Nine, p1075

[5] IDDC (1998) *Lessons from the South: Making a Difference*, An ID and DC Seminar on Inclusive Education, Agra, India. Elwan, (1999) ibid, p33

[6] AusAID, (2001) *Guiding Principles for Australian Assistance for the Inclusion of PWDs in Development Aid Activities*, AusAID: Australia

[7] The Bill of Rights is made up of the *Universal Declaration of Human Rights* (1946), the *International Covenant on Economic, Social and Cultural Rights* (1966) and the *International Covenant on Civil and Political Rights* (1966)

[8] *International Convention on the Elimination of all forms of Racial Discrimination* (1969), *Convention on the Elimination of all forms of discrimination against women* (1981), *Convention against Torture and other cruel, inhuman and degrading treatment or punishment* (1987) *and the Convention on the Rights of the Child* (1989)

## NGOs wake up to inclusion, but action needs to follow

Recent studies in Europe and Australia have explored both the participation of disabled people in NGO planning[9] and their inclusion in overseas development and humanitarian aid activities.[10] Both draw similar conclusions, that international development and humanitarian aid organisations are beginning to recognise the need for, and see the benefits of, including disabled people, but still need to do much more. Chapuis draws from other studies in India, Rwanda and the UK, and concludes that although disabled people are beginning to be included in development processes they are not yet partners with equal standing.[11] The European study suggests that the NGOs most effective at involving disabled people in their planning processes are those that actively engage disabled people's organisations in developing countries, help to strengthen them and encourage their formation where they do not exist.

Where the provision of humanitarian assistance in emergencies is concerned, there is an increasing realisation that particular attention needs to be paid to marginalised groups, such as people with disabilities and older community members, who are less able to queue up for food parcels, and ensure their needs for survival are met. The UK Disasters Emergency Committee (DEC) is emphasising the need for member agencies to ensure that vulnerable beneficiaries are targeted in future interventions. With reference to the DEC evaluation of the emergency response to flooding in Bangladesh in the late 1990s, consultants Janey and Simon Lawry-White[12] state: *'…most agencies reported that provision of relief and rehabilitation for disabled beneficiaries was weak'.* Where older people were concerned: *'…their exclusion was widespread'.*

## programming issues relating to disability in the NGO sector

Changes are evolving in many NGOs which are affecting the manner in which they work with disabled people. McIvor, while field director of Save the Children Fund (SCF) in Morocco, reflects on almost 40 years of evolution of SCF in that country, and looks to the future: *'the most significant challenge facing the organisation is the need to ensure disabled people themselves increasingly inform the action and content of the programmes'.*[13] Changes in SCF programmes have included a move from institutional care, to community based solutions and more recently to a more integrated approach, where disabled children are included in their general programmes. This reflects a broader trend away from only involving disabled people through projects with a special focus – such as community based rehabilitation (CBR) or the provision of artificial limbs – towards an attempt to include disabled people in all development programmes.[14]

Changes are evolving in many NGOs which are affecting the manner in which they work with disabled people

World Vision is another organisation which is beginning to make this move. In Burma a

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[9] Flower J, Wirz S, (2000) *Rhetoric or reality? The participation of disabled people in NGO planning*, Health Planning 15 (2), pp 177-185

[10] Culnane A, (2001) *Information package concerning the inclusion of people with disabilities as participants and beneficiaries in overseas development activities*, Study carried out for ACFOA, Australia (unpublished)

[11] Chapuis L, Flower J, et al, (2000) *Collaboration in disability policies – collaboration between stakeholders of disability policies in the South and in the North*, International Journal of Rehabilitation Research 23, pp 81-89

[12] Lawry-White, Janey and Simon, (2001) DEC Evaluations Synthesis Report

[13] McIvor C, (1995) in *Disability and Integration in Morocco. In our own words* in Save the Children Fund, Morocco (eds), Save the Children Fund: London, pp 83-98

[14] Jones H, (1999) *Including disabled people in everyday life,* SCF: London

number of CBR projects were initiated in the 1990s, but now disabled people are being included in the educational, health and income-generation activities of all World Vision's community development programmes. In Mandalay, one of the projects began as a CBR project and has now evolved into a wider community development programme. This has meant that each of the community development committees has disabled members. The norm in much of the world, that disabled people are relegated to the fringes of society, has been reversed here and disabled people are at the centre of the development process. Similar moves are being made by World Vision in Vietnam but, due to an initial reluctance on the part of donors to fund this integration, they are having to implement this in stages. Importantly, this growing focus on integration is raising awareness and changing and challenging perceptions amongst donors.

## Isolation is an issue the world over

**Disabled children and adults are often hidden away, some never leaving the family home. One of the authors recently met two Burmese neighbours in Rangoon. Khaing Moe Thu is six and spends her days lying on her back. She has done so for the last two years since she grew out of her 'appropriate seating'. Visiting friends and family treat her like a baby due to her prone position. Evidently her physical, mental, emotional and social development is being impaired through lack of any stimulation or social interaction. Next door lives Cho Cho Myaing. She has never left the home where she was born more than 30 years ago. She is physically unable to move around and so relies on her frail elderly mother. When we arrive she has been propped up in a sitting position but due to contractures in her neck is unable to have eye contact with us. The conversation that follows is all about her, but she is excluded from it. Eventually her mother has had enough and after a great effort, manoeuvres her daughter and supports her head with a pillow. At last eye contact is established and she joins in the conversation. Myaing is a keen reader, it is her greatest love in life. Discussion follows about the books that she reads. This skill was not acquired at school as she never attended, but she was taught by her younger brother. If only Myaing had been given the basic opportunities that most take for granted who knows what she could have achieved – High School, university, marriage,[15] work and the ability to support herself and her family. Instead she was denied these and is now afraid to leave her house, the only four walls she knows, and has an uncertain future with her mother who is getting frailer by the day.**

Flower J, Informal project interview, Burma. (2001)

In Armenia, the level of awareness in society regarding children with disabilities is very low, and the concept of a child with a disability as an equal member of society, with the right to live among others, is still relatively new. Under the Soviet system, citizens with disabilities were totally isolated from society at childhood, and considered incapable of functioning in a 'normal' capacity with the general population. This widespread practice of discrimination continues today. Most children with disabilities live very isolated lives, either in their homes or in institutions. Community services for children with disabilities do not exist, and very few of these children have the opportunity of normal school interaction since most do not attend regular schools. The lack of any community support networks, or other resources that families need for raising a child with a disability deepens the isolation.

World Vision has established the Child Inclusive Education Development Project (CIED) to begin to address issues such as these. The CIED Project evolved in response to the request of the Ministry of Education and Science of Armenia to assist in reforming special education. The CIED Project began in 1999 (funded by UNICEF, World Vision and Ireland Aid) with the aim of introducing the philosophy of inclusion and laying down a foundation for inclusive pre-school education. Different extra-

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[15] Having a disabled person in the family is sometimes thought to damage marriage prospects. A disabled man is much more likely to marry than a disabled woman. ESCAP states *'Universally, the incidence of marriage for disabled women is lower than that for disabled men'*, and notes that in Nepal, where marriage is the norm for women, 80% of women with disabilities are reported to be unmarried (Paudel Sushila in a paper contributed to the *Training Workshop for Women with Disabilities*, June 1995, Bangkok, cited in ESCAP (1995). In China, 52% of disabled women over 18 years old are unmarried (CDPF 1995)

curricular activities and field trips were arranged at kindergartens so that children and parents of both disabled and non-disabled children became engaged in the promotion of inclusive education. To increase parents' awareness about children's development, special booklets were developed and printed for dissemination.

The principle of involving all parents and all sectors of society is essential. The basic right of disabled people to be included is not going to be achieved by disabled people campaigning for their rights alone, vital as this is. Society at large needs to be made aware of its responsibility and the benefits of involving all.

Other governments around the world are now giving thought to inclusive education, as they strive towards Primary Education for All.[16] Uganda's radical Universal Primary Education policy provides for free education for four children per family. Any disabled child must be included in the four, as should at least two girls. The Mauritanian government, having never been able to afford to go down the special institution route, is now undertaking a study with funding from the World Bank to assess the educational needs of disabled children and how they can be met. They recognise that currently only a tiny percentage of disabled children are included in the educational system. In Bangladesh it is acknowledged that a large proportion of disabled children could readily be included in mainstream education. However, mainly due to lack of information and negative attitudes, most disabled children are deprived of such education. The Ministry of Welfare in Bangladesh acknowledges that education is, and will be, the fundamental requisite for any development. A development process which excludes disabled children from education, cannot be considered appropriate.[17]

Some NGOs, including Oxfam, VSO and SCF, have officers to ensure that disability is on their agendas. DFID recently published a paper 'Disability, Poverty and Development'[18] which establishes a firm case for ensuring that disabled people's needs are addressed in all poverty alleviation work. World Vision Australia and the other members of the Australian Council for Overseas Aid Disabilities Network have worked with AusAID to draw up guidelines for the inclusion of people with disabilities in development aid activities. Yet despite this trend, according to a report from the Ministry of Welfare in Bangladesh: '*Disabled people are still so often excluded from most of the existing governmental and non-governmental development programmes.*'[19]

In Bangladesh it is acknowledged that a large proportion of disabled children could readily be included in mainstream education

It is important that all governments and NGOs build upon these positive initiatives. Not only should all organisations have proactive strategies to include disabled people, but also everyone in these organisations should be encouraged to take the issues on board. Towards this end, World Vision UK are holding a series of awareness raising seminars and events for all of its staff. Without such action, disability will remain a specialist area tacked on the side of the mainstream work of organisations, rather than being an integral part. The inevitable result of this would be the further marginalisation of the world's poorest people and the failure of governments and NGOs alike to meet their poverty alleviation targets.

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[16] mentioned on the UNESCO website: www.unesco.org/education

[17] Ministry of Welfare Bangladesh, (1999) *Towards Equalisation ESCAP Decade of Disabled Persons, 1993-2002, A Review of Progress in Bangladesh,* ActionAid: Dhaka, p23

[18] Department for International Development, (2000) *Disability, poverty and development*, DFID: London

[19] Ministry of Welfare Bangladesh, (1999), ibid, p21

## conclusions and recommendations

- NGOs, governments and communities are starting to wake up to the need to include and give a voice to disabled people in development processes. As one of the stakeholders they should be involved at every stage, from project design and implementation, to monitoring and evaluation.
- There needs to be a move away from simply providing special programmes for disabled people, to ensuring that they are included in all general humanitarian aid and development programmes.
- Organisations that have begun to catch up with the issues around disability need to make sure that it is on everyone's agenda, not just that of a few 'specialists'.
- NGOs and governments should actively seek to engage disabled people's organisations in the countries and localities where they work. Where appropriate they should help to strengthen them and encourage their formation where they do not exist.
- Action by disabled people needs to be complemented with action by the rest of society.
- Disabled people should be adequately represented amongst NGO staff and decision-making bodies such as development committees.
- Primary Education for All should mean primary education for all, and strategies must be made to include disabled people.
- Passive non-discrimination is not enough. Programmes must proactively attempt to reach the most marginalised of children and adults.

Many organisations now acknowledge that there are many ridges and troughs in the 'development playing field'. Some have even got the roller out of the shed to do something about it. However, there is a long way to go to ensure all people can participate fully in the thousands of community development programmes around the world. Until they do, sustainable community development, which strikes at the heart of poverty, will continue to be elusive.

World Vision Albania is starting to establish child inclusive education projects to breakdown conventional barriers to inclusive education. It is hoped the programme will expand.

# we are children too!

## are disabled children included in the rights agenda?

*'Everybody's got something different about them, and some things are just more different than others. But we're all – I don't know – different in different ways'.*[1]

**Rachel Hurst OBE & Gerison Lansdown**

*Disability Awareness in Action & Rights for Disabled Children*

### introduction

There is international recognition that all children are subjects of rights and that governments have obligations to protect, promote and fulfil those rights. Unfortunately this protection is still not, despite the Convention on the Rights of the Child (CRC), being properly implemented for disabled children.

### incidence of disabled children

It is difficult to assess the exact numbers of disabled children as research has different definitions of impairment and of disability. UNICEF estimates that there are 120 million disabled children in the world, others estimate 150 million children.[2] That is 2-4 per cent of populations. They are children with physical, sensory and intellectual impairments and children with mental health problems. In developing countries approximately half become disabled in the first 15 years of life. There are some countries where 90 per cent of disabled children do not survive beyond the age of 20 and 90 per cent of intellectually impaired children do not survive beyond the age of five years.[3]

The past decade has been witness to many developments which have contributed to the incidence of disability – landmines, HIV/AIDS, increasing poverty in many developing and some developed countries. Non-governmental sources also place particular emphasis on factors related to the environment, air and water pollution, scientific experiments conducted without the informed consent of the victims, terrorist violence, wars, intentional physical mutilations carried out by the authorities, and other attacks on the physical and mental integrity of persons, as well as violations of human rights and humanitarian law in general.[4] These trends are running counter to the progress being made in other fields to eliminate major causes of impairment such as poliomyelitis, measles and lack of access to safe water.

### the status of disabled children[5]

Here is just one experience:

*'To be imprisoned inside one's own body is dreadful. To be confined in an institution for the profoundly retarded does not crush you in the same way; it just removes all hope. I went to St. Nicholas Hospital when I was three. The hospital was the state garbage bin. Very young children were taken into permanent care, regardless of their intelligence. If they were disfigured, distorted, or disturbed then the world should not have to see or acknowledge them. You knew that you had failed to measure up to the standard expected of babies. You were expected to die.'*[6]

If they survive, what do these disabled children face? Despite the endeavours of NGOs, some governments, the UN and other agencies through many excellent programmes and projects to support the inclusion of disabled children in mainstream life, the vast majority of these children are

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[1] 12 year old disabled girl quoted in Cavet, U (1998) *People don't understand: Children, young people and their families living with a hidden disability*, National Children's Bureau: London

[2] Roeher Institute (2000) *Including all children: policy goals for achieving progress,* a draft discussion paper for the 6th International Congress on Including Children with Disabilities in the Community, Canada

[3] DAA (1995) *Overcoming Obstacles to the Integration of Disabled People,* UNESCO-sponsored report for the World Summit on Social Development: London

[4] Despuoy, L (1991) *Disability and Human Rights,* Final Report of the UN Special Rapporteur, UN: New York

[5] The facts below are all verified through statistics of the UN, UNICEF, Save the Children and from the DAA database on violations against disabled people.

[6] Crossley & McDonald (1980) *Annoys' Coming Out,* Penguin: Australia

not valued as equal to other children. Assumptions and prejudices about their quality of life often put that very life in jeopardy. They are not seen as capable of or needing love, affection, family life, friendship or play. They are denied development, education (only 2% of disabled children in developing countries have any form of rehabilitation assistance or education), access to their communities and the expectation of being able to participate as adults in society.

Violence and abuse is three times more likely to happen to a disabled child. They are segregated and marginalised in special institutions, day centres and schools. They are defined by what they lack, not by what they are. There is little respect for their dignity, their individuality and integrity. Different cultures and societies have different ways of saying the same thing: that to have a disabled child is a shame and disgrace. Throughout the world, laws and policies regarding genetics, in vitro fertilisation, abortion, resuscitation and infanticide all underline that it is better that a disabled child does not live.

International law has been slow in recognising that disability is a human rights issue – for adults and children

Disability Awareness in Action (DAA), an international information network on disability and human rights, has a database collection of violations of disabled people's rights. This collection, only started in May 1999, already has violations affecting 2,038,044 disabled children, 22% of who are children aged 0-16. (This is a much larger proportion than children are of the disabled population, showing that disabled children are more likely to face violations than disabled adults). Fifty one of those children have died as the result of the violation of their rights.

## the rights of disabled children

International law has been slow in recognising that disability is a human rights issue – for both adults and children. Neither of the International Covenants, on civil and political rights and on economic, social and cultural rights, contain any express provision on the rights of disabled people, nor explicit recognition of disability as a ground for protection against discrimination. However, in their 1994 General Comment on Disability, the Committee on Economic, Social and Cultural Rights stated that:

*'since the Covenant's provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognised in the Covenant'.*

Since 1981 and the International Year of Disabled Persons, the UN has promoted the full and equal participation of disabled people in society. In 1993, following on from the special Report on Disability and Human Rights,[7] all member states agreed the UN Standard Rules on Equalisation of Opportunities for Persons with Disabilities which outlines ways in which member states can ensure the full and equal participation of disabled people. These Rules do contain some references to disabled children as a group requiring special protection, but they are not a legal or enforceable instrument. They have been monitored by a Special Rapporteur, Bengt Lindqvist and a Panel of Experts from the international disability organisations and the work is resourced by voluntary funds. This monitoring has shown the widespread discriminatory attitudes toward disabled children and highlighted the need to make the Rules more effective with regard to disabled children.

It was not until 1998 that the Commission on Human Rights finally resolved that disability was a human rights issue.[8] And it was only in

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[7] Elwan, (1999) *Poverty and Disability; a background paper for the World Bank Development Report*, Washington

[8] United Nations, (1998) Commission on Human Rights resolution 98/31, Geneva

May 2001 that the World Health Organisation finally revised their definition of disability, not as a personal characteristic, but as the interaction or outcome between impairment or functional limitation and the negative impacts of the environment.[9] It is perhaps important to note that the international organisations of disabled people had been saying that disability was a rights issue since 1981, and it is they who have worked hard to bring about the same recognition within the UN system and within some national governments.

### the Convention on the Rights of the Child

The Convention on the Rights of the Child (1989), however, does include disabled children. Disability is listed as grounds for protection against discrimination, and Article 23 is specifically about disabled children and their needs. And the whole Convention is relevant for the human rights of disabled children. Of special significance for disabled children is that the Committee on the Rights of the Child, the international body monitoring states progress in implementation of the Convention, identified four general principles which need to be considered in the implementation of all other rights. These four principles are:

> They are not seen as capable of, or needing, love, affection, family life, friendship or play

- **Article 2 – non-discrimination** This article not only requires governments to respect the equal rights of all children but also imposes active obligations on them to ensure that children are not discriminated against in the exercise of any of their rights. The article does prohibit differentiation between children. For instance, it would be acceptable to offer additional educational assistance or facilities to a disabled child if this was needed in order to help them fulfil their potential, but offering a different or lesser education, simply because of disability would constitute a breach of the article.

- **Article 3 – the best interests of the child.** This principle applies to actions affecting both individual children as well as children as a group. However, adults frequently make decisions and take action in respect of children, seemingly in their best interest, though it is often not the case. For example, placing disabled children in large institutions, subjecting them to painful surgery and rehabilitation in attempts to make them 'normal', failing to provide opportunities for education on the assumption that they are not competent.

  All these actions when assessed by the Convention's four principles illustrate the reality of the best interests. Does it give the disabled child the same opportunities as other children? Does it exclude them from family life, social networks and friendships? Does it result in social exclusion and lack of participation? Does it expose them to stigma and prejudice? Does it threaten their humanity? Answers to these questions can ensure the best interests of the disabled child and also provide appropriate solutions.

- **Article 6 – the right to life, survival and development** The right to life must be protected equally for all children and governments are required to ensure to the maximum extent possible the survival and development of all children. This means that disabled children, like non-disabled children, must be provided with the support, resources and care necessary to promote the fulfilment of their potential. It also means that negative assumptions of quality of life and humanity should not impact on this right to life, survival and development and in any way lessen the protection.

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[9] World Health Organisation World Assembly, (May 2001) resolution WHA54.21, Geneva

- **Article 12 – the right to be listened to and taken seriously.** Children are entitled, as of right, to be consulted when decisions that affect them are being made and must be recognised as active agents in their own lives. Too often it is the silence and invisibility of disabled children which continues the persistence of discriminations against them both as a group and as individuals. It is only through listening directly to the experiences of disabled children that adults gain awareness of the extent, nature and impact of discrimination, isolation and abuse on their lives.

### progress in implementing the rights of disabled children

In February 1996, the Committee on the Rights of the Child reported to the Commission on Human Rights Sub-Commission on Prevention of Discrimination and Protection of Minorities the concerns that they had identified from examination of State Parties' reports with regard to disabled children. Their major concerns arose from finding widespread discriminatory and negative attitudes toward disabled children, inadequate access to health and social care services, low numbers of disabled children enrolled in schools, negative impacts of budgetary reductions specifically targeting disabled children and the lack of international assistance and exchange of information to address this situation.

In 1997, the Committee on the Rights of the Child agreed to hold a Day of General Discussion on the rights of disabled children. Two disabled young girls from South Africa, Chantal Rex and Pearl Mokutuone, were invited to make a presentation. Chantal spoke of how her family had been forced to move from their rural village to Cape Town in order to get medical and educational support and her problems with mobility. Pearl, deafened by riots in Soweto, spoke of her frustration and loneliness because of communication difficulties and superstitious attitudes to disabled people. Their words gave validity to previous presentations by disabled adults, who had described the continuing violations of disabled children's right to life itself. The two girls' presentations moved and inspired the Committee who then agreed fourteen recommendations.[10]

They called on states to actively challenge attitudes and practices which discriminate against disabled children

Among other things, they called for a review and amendment of laws persisting in many countries affecting disabled children which are not compatible with the Convention, particularly in regard to the right to life, survival and development (including discriminatory abortion laws), the right to education or those laws which segregate disabled children in separate institutions for care, treatment or education. They called on states to actively challenge attitudes and practices which discriminate against disabled children and deny them equality of opportunity, including infanticide, traditional practices prejudicial to health and development, superstition and perception of disability as a tragedy.

The Committee agreed to participate, alongside international disability and children's organisations, in a working group that would follow-up on these recommendations. Their programme of work includes in-depth research on violations and examples of good practice, and providing evidence to the pre-sessional meetings of the Committee on the Rights of the Child on the situation of disabled children in the country reports under discussion.

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[10] Recommendations of the Committee on the Rights of the Child (Oct 1997), General Discussion on the Rights of Children with Disabilities, Geneva

## monitoring and addressing rights

Despite these developments, the extent to which the rights of disabled children are being monitored and addressed is far from adequate. Article 23, which is grouped in the cluster of articles on health and welfare, focuses on the individualised provisions of 'special' needs, reaffirming that it is the unhealthy child that should be changed to fit society rather than society changed to welcome and include the child. The article places no obligation on states to take measures to create inclusive and enabling environments and because Article 23 does not reiterate non-discrimination it could appear that special provisions can be discriminatory. Committee guidelines only request information about disabled children under Article 23 and therefore information on the right to life, right to play, family life etc. is not collected by the Committee in the context of a disabling environment.

The scale and severity of human rights violations against disabled children continues, but they have not yet received the international attention they deserve. The Convention on the Rights of the Child has brought other significant areas of children's rights to the world's attention. Issues such as sexual exploitation, child labour, children in armed conflict and violence against children have been widely acknowledged as rights issues demanding urgent action. However, to date, no comparable interest has focused on the experiences of disabled children. They remain largely invisible, hidden within families or institutions, vulnerable to neglect of their economic social, cultural, civil and political rights.

## good practice

Despite the scale of violations and discrimination toward disabled children, around the world NGOs, UN agencies and governments are working hard for change. There are concrete examples of policy and practice which indicate what can be achieved with vision, commitment and a willingness to listen to disabled children and their families. Below are just some examples - there are many others.

- **RESCU, Zimbabwe** – started by parents of intellectually impaired children and now providing employment for 70 disabled people of different impairments who provide wheelchairs and technical aids and sell them as a commercial concern.
- **Divine Light Trust, India** – after 35 years, a school for blind children has been changed – without an increased budget – into a resource centre training teachers in mainstream schools to integrate blind children into their schools.
- **Universal Primary Education, Uganda** – provides free primary education for a maximum of four children per family, to include two girls and any disabled children.
- **South African Constitution** – prohibits discrimination against disabled children (and adults) and recognises sign language as an official language. The South African Schools Act recognises the right of deaf learners to learn through the medium of sign and for disabled learners to be given first preference in local, ordinary schools.

## further actions to promote the rights of disabled children

As has been illustrated the scale of discrimination and abuse of human rights against disabled children is intolerable. We see the impairment, not the child. We expect them to put up with quite different situations than we do non-disabled children. We do not regard their lives to be as important or worthwhile as those of non-disabled children. We need to establish the political and legal frameworks backed up by practical action which will achieve equal rights and opportunities for all disabled children. These actions need to be taken as a matter of urgency and by all member states.

# 10 point action plan

## promoting the rights of disabled children

**Rachel Hurst OBE & Gerison Lansdown**

*Disability Awareness in Action & Rights for Disabled Children*

1 **end discrimination** – Introduce non-discrimination legislation with an explicit reference to disability as a ground for protection against discrimination

2 **ensure equal rights to education** – Spell out in education legislation that the right to education for all children includes all disabled and non-disabled children

3 **promote inclusion** – Establish clear goals and timescales for moving towards inclusive education for all children

4 **make disabled children visible** – Disaggregate data to ensure that disabled children are made visible in statistics relating to, for example, poverty, abuse, education, institutional care

5 **expose and challenge neglect and abuse** – Undertake surveys and research into the experiences of disabled children to expose and highlight abuses of their rights and enable them to contribute towards the development of policies to bring them to an end

6 **challenge prejudice and ignorance** – Promote public education campaigns to overcome prejudices, misconceptions and lack of understanding of the nature and implications of disabilities, and to promote respect for the equal rights of disabled children

7 **establish children's rights commissioners or ombudspersons for children** – Introduce statutory, independent bodies to monitor, promote and protect the rights of all children, including disabled children

8 **end violence against children** – Introduce legislation to end all forms of violence against children in families, schools, and all other institutions in which children live, backed up by campaigns of zero tolerance of violence against children and introduce mechanisms through which children can challenge the violence and abuse to which they are exposed

9 **promote participation** – Introduce legislation to provide children (as individuals and as a group) with the right to participate in decisions which affect them in families, in schools and in local and national government and ensure that in all consultation mechanisms, disabled children are fully and effectively represented

10 **remove disabling barriers** – Undertake analysis, in collaboration with disabled adults and children of the barriers – physical, cultural, social and economic – which impede the inclusion of disabled children, and develop a 10 year strategy to create an inclusive environment which facilitates respect for all the rights of disabled children

# a unified voice for people with disabilities

## actively campaigning for change in Uganda

**Benon Ndaziboneye**

*Programme Officer for Capacity Building and Rehabilitation Services National Union of Disabled Persons of Uganda*

### introduction

Formed in 1987, the National Union of Disabled Persons of Uganda (NUDIPU) is an indigenous umbrella organisation of people with disabilities that brings together all categories of disability including physical, sensory and mental impairment.

NUDIPU's mission is to create a unified voice for people with disabilities (PWDs). The only NGO of its kind to reach from village to national level, NUDIPU is the official spokesman of PWDs in Uganda and works with the government, civil society organisations and the general public to advocate for the equalisation of opportunities and involvement in the policy planning and implementation of disability programmes. Its main purpose is to influence the provision of services in favour of PWDs in Uganda.

In Uganda, negative attitudes towards PWDs are rampant in society from families through communities, government departments and NGOs up to very high-level government authorities. For instance, most families believe that whenever a person acquires a disability they will never be of any use to society and should stay at home and be cared for. There is seen to be little point in sending them to school or training them in domestic activities. As a result, there are currently a large number of PWDs in Uganda who are not educated and, having no profession, cannot be employed in the formal sector.

It is also significant that most development programmes are designed in a standard way as if the whole population were homogeneous - to the extent that persons with disabilities are left out because of physical, technological or even social barriers.

NUDIPU recognises the urgency of addressing these issues, and is actively campaigning for change. This article details just a few of our current campaigns.

### education

NUDIPU believes that the best tool for empowering a disabled person is to give him or her a quality education. This not only equips them with employable skills but also provides psychological empowerment, builds up their confidence and increases society's acceptance of that individual.

For the last ten years we have been campaigning for the state to commit to providing access to education for all. Our state has responded by making provision in the Constitution for education to be a right for all Ugandans without discrimination. Subsequently the Children's Act of 1996 requires the state, community and families to put in place programmes and provide the necessary equipment and materials for children with disabilities so that they can access education and other services.

> most families believe that whenever a person acquires a disability they will never be of any use to society

In 1996, the Government launched a policy of Universal Primary Education. In this policy the Government made provision for four free child places per family to make it less of a burden for parents to meet the cost for any remaining children. In response to our advocacy, the Government decided that, of these four, children with disabilities should take priority. This intervention alone has increased the enrolment of children with disabilities by 600 per cent in the last five years.

## challenges

Although this trend is positive in terms of quantity, it has created other challenges for government and other service providers as listed below:

- There are still a large number of visually impaired children who do not have appropriate equipment and access to trained teachers to enable them to have the same quality of education as their sighted counterparts. Even those who can be reached by a special needs teacher often do not receive adequate attention due to a high student-teacher ratio.
- Deaf children suffer an even worse problem because of the lack of a medium of instruction in schools where there are no special needs teachers. Worse still, there is no secondary education for the deaf in Uganda yet.
- The majority of the school structures have not been designed for the access of children with movement disabilities, especially wheelchair users. Therefore, once the initial excitement of attending school has declined, many of these children drop out of school because of the above challenges.
- The Government and other providers have been very slow in identifying and allocating the kind of resources that would mitigate this situation.

Although the Government has adopted a policy of inclusive education, it has only addressed the problem of numbers but not the problem of quality and access. There is still a high level of disparity between the two. Nevertheless, we do acknowledge that a half-baked cake is better than no cake at all.

> The Government has only addressed the problem of numbers, but not the problem of quality and access.

## finding solutions – engaging in advocacy

To support our campaigns, NUDIPU has a policy research and documentation unit. Our research shows that the Government, development partners, our local councils, communities and households have more resources at their disposal than are currently being utilised to mitigate problems. Much of this can be attributed to faults in development planning, programme design and policy.

On the one hand these faults could be due to a simple lack of awareness of the needs of children with disabilities and of the appropriate interventions needed. However, on the other there may be a level of unwillingness to go that extra mile to allocate resources.

Our activities to combat these issues are as follows:

- In collaboration with the Department of Special Needs Education of the Ministry of Education and other stakeholders, we run awareness campaigns to sensitise civic authorities and development planners about the needs of PWDs and the materials, human resources and infrastructure needed to meet these needs. We package these needs together with international and national legal instruments to demand their commitment. We publicise these activities through the mass media, organise sensitisation seminars and workshops, and produce regular publications.
- We also try to influence different policies directly, by lobbying to sit on various technical advisory committees and policy-making fora. We have been very successful at this and now sit on a

number of different government councils and task forces. Most of these agencies are opening up and recognise our contributions and invite us to participate in the development and delivery of services.

- Another strategy is to influence legislation. This we do through our representatives in parliament but also by running lobbying meetings with other members of parliament and local authorities.

### achievements

NUDIPU's campaigns have been successful in a number of ways and some of our most notable achievements are listed below.

- Sign language for the deaf has been enshrined in the National Constitution as one of the languages of Uganda, and is accepted as a medium of instruction in institutions of learning.
- In recent years, as a move towards addressing the issues of quality and equal distribution, there has been a Presidential pledge to identify model schools in all regions of the country and resource them adequately.
- The structural plans for the construction of school classrooms and other facilities have been designed with provisions for the accessibility of people with movement disabilities.
- Special Needs Education has been introduced into the teacher training curriculum to address the lack of trained teachers for those with special educational needs.
- A Special Needs Education Department has been created and is providing Braille materials for some children (although this it is still a drop in the ocean).

### assistive devices

One of the most severe problems for PWDs is the lack of appropriate assistive devices both for mobility and for occupational purposes. Those devices produced in the country are still too costly for PWDs, the majority of whom come from poor families. Most of the devices for the blind are imported and are terribly expensive. Those who receive them are assisted by some NGOs and a few government departments. However, because of their related costs, both government and NGOs service providers have been very reluctant to invest in this area.

While the Constitution and various acts of parliament provide for this, these needs have received the lowest share of government financial allocation. Even donors feel this is a government responsibility. As such, they allocate meagre resources, or none at all. Yet people with disabilities believe that an assistive device could possibly give about 75 per cent rehabilitation for a person who depends on it. For instance a hearing aid can liberate a person hard of hearing and a Brailler and a typewriter can provide employment to a blind person. In the same way, a wheelchair gives greater freedom to a person with movement disabilities.

> Even donors feel this is a government responsibility. As such, they allocate meagre resources, or none at all

In light of all this, NUDIPU is lobbying the Government and funding agencies to provide assistive devices either free of charge or subsidised to an affordable level. In addition, we are advocating for tax exemption on imported materials for manufacturing mobility aids and directly imported special equipment for PWDs.

### micro financing

In Uganda there have been a lot of programmes to combat poverty and one of the most popular approaches to poverty reduction has been to stimulate self-employment through micro-credit. To this end the Government has instituted several micro-financing schemes. As the majority of people with disabilities have not had enough education for formal employment, NUDIPU has lobbied government to make special provision for them, and some money is now trickling down. This has been done through our economic empowerment programme.

We are also engaged in training PWDs in small-scale enterprise development and loan management, so that they have the capacity to qualify for credit

However, as micro-financing is still very much dominated by the private sector there are many issues still to be tackled. Non-governmental micro-finance institutions have been very slow to open up their services to disabled people as they fear that PWDs may never be able to pay back their loans. Unsurprisingly then, the conditions set by these institutions discourage PWDs from accessing their services. To overcome this challenge, NUDIPU has been negotiating with the institutions to offer special concessions to PWDs. We provide assurance that PWDs can perform to the optimum and give examples of where they have been successful. We are also engaged in training PWDs in small-scale enterprise development and loan management, so that they have the capacity to qualify for credit.

### conclusion

By creating a unified voice for people with disabilities in Uganda, NUDIPU has achieved a great deal of success through its campaigning. Whether in terms of educational provision for disabled children or micro-finance opportunities for adults with disabilities, our determination to gain an equal footing for disabled people in our society has persuaded the Government, civil society organisations, communities and families to take positive action. However, with many more challenges to face and obstacles to overcome, there is still a great deal of work to be done.

# rethinking ‘care’ from the perspective of disabled people

## World Health Organisation recommendations to member states (draft)

**Professor Colin Barnes**

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### introduction

Although it is now two decades since the United Nations’ ‘International Year of Disabled Persons’, disabled people across the world still encounter severe economic, political, cultural and social deprivations. Whilst this is the case in all countries, whether high or low-income, ‘developed’ or ‘developing’, it is particularly acute in many low-income nations, where medical and rehabilitation resources are disturbingly scarce, and where abject poverty is a common experience.

There is a growing disenchantment with current provision among both users and providers that can be traced back at least to the 1960s, if not before, and especially in developing countries. Also, this situation is widely attributed to the inadequacy and/or ineffectiveness of current 'care' services, both medical and rehabilitational, for this increasingly large section of the world's population. Health and rehabilitation can no longer be understood solely in terms of orthodox medical interventions and conventional notions of ‘care’. These centre almost exclusively on the perceived limitations of individuals rather than on society’s failure to accommodate disabled peoples’ needs.

The word ‘care’ has many connotations: have a liking or desire for, to be concerned about or to look after. It is also associated with the concepts of ‘protection’ and ‘supervision’ and is used with reference to many sections of the community. We care about family and friends. We care about particularly vulnerable groups such as small children, older ‘frail’ people, and people with serious and life threatening illnesses. When applied to disabled people ‘care’ usually means ‘to be looked after’, ‘protected’ or ‘supervised’. From disabled peoples’ perspectives this is an overtly patronising and, indeed, unhelpful use of the term. First, it implies that disabled people can never achieve any degree of independence within their communities. Second, and most important, it conceals the fact that there is overwhelming evidence that many of the problems encountered by disabled people are the result of society’s failure to care about their needs. Particular issues of concern are that:

- The main causes of chronic diseases and long term impairments in both high and low-income nations throughout the world are poverty, inadequate sanitation, poor diet, bad housing, environmental pollution, industrial and road traffic accidents, violence and war.
- Whilst there is a growing need for the most basic of medical treatments across the globe, and particularly in low-income countries, a disproportionate amount of resources, both financial and human, are increasingly being poured into the development of costly medical treatments which will benefit only a relatively small percentage of the world's population.
- Irrespective of diagnosis and subsequent labelling, in societies geared for non-disabled living all chronic conditions and impairments have both physiological and psychological consequences.
- Rehabilitation and related interventions are extrememly limited in what they can achieve in terms of enabling disabled individuals to live in a society organised almost exclusively for non-disabled lifestyles.
- Worldwide, people with accredited chronic diseases and impairments encounter various economic, political, cultural and social barriers which cannot be resolved by traditional individualistic, medical type solutions.

The process of 'rethinking care' therefore must go way beyond conventional notions of medicine and rehabilitation, and consider wider and sometimes more contentious issues: economic, political, cultural and social. From this perspective, therefore, to care about disability and rehabilitation means to care about society, how it is organised and about its future.

Responding to this insight, the WHO 'Rethinking Care' Initiative and Conference (Oslo, Norway, April 2001) brought together disabled people and other stakeholders from high and low income countries to identify key issues and propose recommendations for member states to ensure disabled peoples rights in the health sphere. These were based on the first four UN 'Standard Rules on the Equalization of Opportunities for Persons with Disabilities'. These concern the provision of awareness raising, medical care, rehabilitation and support services.[1] The draft recommendations follow.

## recommendations[2]

Although a wide range of views were expressed during the WHO 'Rethinking Care' conference, there was a general consensus among all contributors that a holistic approach that goes way beyond conventional notions of medical 'care' is urgently needed if we are to address the numerous problems associated with disability and rehabilitation.

### a holistic approach: access, legislation and funding

- To reduce unnecessary and escalating health and disability related expenditure therefore states must invest in the eradication of poverty and the development of fully accessible community based services and facilities. These must include medical and rehabilitation services, housing, schools and colleges, public buildings and amenities, transport systems etc.
- States must ensure that 'fully accessible facilities' include access for people with mobility related impairments, accessible information media for people with learning difficulties, sign language interpreters for deaf people, and appropriate support services for people with 'mental health' problems and/or multiple impairments and potentially high dependency needs such as deaf/blind people, for example.
- States must introduce comprehensive mandatory anti-discrimination laws to secure the systematic removal of environmental and cultural barriers to disabled people's meaningful participation at all levels and in all areas – economic, political and social – of mainstream community life.
- States must establish and/or support an independent network of NGOs run and controlled by disabled people that are suitably accountable to members, to advise, monitor and, where necessary, secure through the law courts the implementation of anti-discrimination policies, practices and procedures.
- States must encourage international organisations such as the United Nations and the European Union to devise policies that ensure high-income nations, international financial institutions, and transnational corporations put more resources into the development of health related services in low-income states. Care must be taken to ensure that these contributions are provided as a right and without any legal or moral obligation on the part of recipient nations.

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[1] See UN (1993): *Standard Rules on the Equalisation of Persons with Disabilities,* United Nations: New York

[2] The following section is taken from, *Rethinking care from the perspective of disabled people – Conference report and recommendations* (WHO, August 2001). At the time of publication, these recommendations were still in the process of being approved by WHO and are therefore subject to change. NB. For this reason, the WHO/Standard Rules preferred term 'persons with disabilities' may not always be used

### medical services

- States must ensure that access to high quality medical services and facilities is a basic human right and must be free and available to all people regardless of the nature and/or severity of impairment, age, gender, race, ethnicity, and sexual orientation.
- States must ensure that the right to life is assured in the delivery of medical and health services to all people and especially to disabled people regardless of the nature and/or severity of impairment, age, gender, race, ethnicity, and sexual orientation.
- Given that these recommendations have important ethical and economic implications for the future development of medical services, states must ensure that all stakeholders and especially disabled people and their representatives are fully and equally involved in discussions of how medical and health services budgets are allocated and used.
- High-income states that actively recruit medical and health service personnel from low-income countries must be legally bound to pay the full cost of recruitment and training of new staff and to compensate for the loss of expertise to low-income nations.
- States must introduce mandatory policies to ensure that all medical services and facilities are made fully accessible to all disabled people and their families. This must include accessible physical environments, information services for people with visual impairments, deaf people, and people with learning difficulties, and suitable support services for 'mental health' systems users, and people with complex and/or multiple impairments such as deaf/blind people, for example.

High income states that actively recruit medical and health service personnel should compensate for the loss of expertise to low income nations

- States must take the appropriate steps to secure disabled people's active and meaningful involvement at all levels and in all areas of the organisation, development and delivery of mainstream medical services.
- States must introduce appropriate measures to secure the equal and effective treatment of all disabled people within mainstream medical services. Particular attention must be paid to the needs of disabled women, disabled children, people with communication difficulties, people with learning difficulties, 'mental health' systems users and survivors, and people with severe, complex and/or multiple impairments.
- States must ensure that medical services are provided in hospitals or residential institutions only when absolutely necessary and that where hospital based treatment is considered appropriate patients should not be discharged prematurely and certainly not without their or their family's consent.

- States must ensure that the educational curriculum for trainee medical and health service personnel includes core components on impairment and disability related issues and concerns. Steps must be taken to ensure that suitably qualified disabled people should be actively involved in the development and delivery of these elements of the medical training programmes.

- States must ensure that appropriate measures are taken by medical schools and similar establishments to recruit and train disabled people as doctors, nurses, and related medical service personnel.

- States must take steps to ensure that unwanted and unnecessary medical and related interventions such as sterilisation, abortions, electric shock treatments, experimental drug therapies, and/or corrective surgeries are not imposed on disabled people without full, proper and accountable consultation and consent with all concerned. This might include disabled individuals, their families and independent NGOs run and controlled by disabled people.

- States must introduce mandatory procedures to ensure that assessment and certification procedures for accessing medical and disability related services should be determined by disabled people, their families, and independent NGOs.

- All states must introduce policies to ensure that in crisis situations such as wars, floods, earthquakes etc. emergency services are adequately equipped and prepared to provide appropriate medical treatments and support for disabled people and their families.

### rehabilitation services

- Medical services should give disabled people optimum functioning at the individual level. But their successful rehabilitation into the mainstream of community life cannot take place without the effective removal of environmental and cultural barriers to their participation. Therefore, all states must ensure that the primary aim of all rehabilitation programmes must be the systematic removal of these barriers. This process must involve meaningful consultations with disabled people, their families, and representatives of NGOs run and controlled by disabled people.

- To facilitate effective barrier removal at the local level, states must establish suitable training programmes for the education and training of locally based community workers. The aim of these schemes must be to provide local people with the knowledge and skills to identify and remove environmental and cultural barriers to disabled people's participation through the identification and effective mobilisation of appropriate local resources. States must ensure that local disabled people, their families, and disabled representatives of independent NGOs are fully involved in the education and training of these community based professionals.

> all states must ensure that the primary aim of all rehabilitation programmes must be the systematic removal of these barriers (environmental and cultural)

- To avoid the creation of new barriers to participation, states should ensure that disabled representatives of independent NGOs are fully involved in the development of all future community based services, facilities and projects.

- States must ensure that where necessary disabled individuals are provided with the appropriate education, training and skills to secure their meaningful participation in the economic and cultural life of the local community.

- States must ensure that the particular interests of disabled women, disabled children and people with potentially complex support needs such as people with learning difficulties, ‘mental health’ system users and survivors, deaf and deaf/blind people, are fully addressed in all community-based programmes and projects.

**support services**

- States must ensure that support services for disabled people and their families include appropriate technical aids and assistive devices, interpreters for deaf people and personal assistance services. Particular attention must be paid to the interests of disabled women, disabled children and people with potentially complex support needs such as people with learning difficulties, ‘mental health’ system users and survivors, and deaf/blind people.
- States must introduce appropriate legislation to ensure that access to these services is a basic human right for all disabled individuals and their families, and that provision is free and not dependent on the ability to pay.
- States must ensure that disabled people, their families and disabled representatives of independent NGOs are fully involved at all levels and in all areas of the development and delivery of community-based support services.
- States must ensure that the development, production and delivery of technical aids and assistive devices is sensitive to local environments and cultures.

States must ensure that the development, production and delivery of technical aids and assistive devices is sensitive to local environments and cultures.

- States must introduce legislation to prevent the distribution in low-income countries of unwanted and inappropriate technical aids, equipment, and associate support services.
- States must encourage and support the development of community based self-help groups and support services run and controlled by disabled people.

**awareness raising**

- States must ensure that awareness raising campaigns focus on the disabling consequences of environments and cultures that do not take account of the needs of disabled people and their families regardless of the nature and/or severity of impairment, age, race, ethnicity, and sexual orientation.
- States must ensure that awareness raising campaigns target all sections of the community including policy makers, politicians, religious leaders, teachers, health and social service professionals, disabled people and their families. This must include those living in long term institutions. Awareness raising amongst disabled people is needed to help disabled individuals develop positive self-identities and a shared disability culture and consciousness.
- States must ensure that all awareness raising programmes are targeted at all elements of the media. Special attention must be paid to the cultivation and support of high profile positive disabled role models within the media.
- States must ensure that awareness raising campaigns are augmented by short training programmes focusing exclusively on disability equality issues. These must be provided for all sections of the community including religious leaders, politicians, policy makers, local government officials, health service professionals, teachers, employers and disabled people and their families.

States must ensure that awareness raising campaigns should go beyond impairment and disability issues, and address the complex relationship between health and wealth within and between countries.

- States must ensure that disabled people and disabled representatives of NGOs are fully involved at every level in the development and delivery of all public awareness raising campaigns.
- States must ensure that awareness raising campaigns should go beyond impairment and disability issues, and address the complex relationship between health and wealth within and between countries.
- Awareness raising campaigns must draw attention to the increasing gap between rich and poor people within and between nations, and its consequences for health and related issues. The increasing commercialisation and unequal distribution of medical and health related services throughout the world is a major awareness raising issue.
- States must urge the UN to establish a UN Convention on the human rights of disabled people.

Disabled people at the World Vision funded vocational skills training centre in Cambodia have seen community attitudes change as a result of their learning new skills.

# the participation of people with disabilities through self-help organisations

**ASM Mosharraf Hossain**

*Programme Manager Action on Disability & Development, Bangladesh*

The aim of this article is to highlight the importance of disabled people's participation in the development process and to raise awareness about the role disabled people's organisations have to play in bringing about social change for a disability inclusive society.

### introduction

Disability is a social issue. To alleviate disability and to bring about social change, people with disabilities need to be able to participate spontaneously in social mobilisation work and this requires conscious organisation and strong leadership.

However, people with disabilities rarely get the opportunity to organise and be empowered since they are so often excluded from the mainstream development process. In this vacuum, the medical professional and community based rehabilitation (CBR) experts have often taken disability as their domain, leaving social discrimination unchanged. However, disabled people can take control of their own lives. They can bring about change within society for their inclusion and access to equal rights. The rights of people with disabilities are established when they feel empowered and their participation is fully observed.

For disabled people to become empowered it is very important to promote a self-help approach. The self help groups (SHGs), also known as disabled people's organisations (DPOs), should not be isolationist but rather act as a tool to bring about inclusion in society. Participation of people with disabilities is the key and crucial element. Self-help organisations of people with disabilities allow their members to explore their critical thinking and to bring about participation in the planning of community development. Furthermore, the unity of people with disabilities from the grassroots to the national level strengthens the disability movement and creates a wave that brings social change nationally.

People with disabilities in many countries have proved themselves to be active partners in the development process and ADD's experience of working with disabled people's organisations across Africa and Asia bears witness to their drive, competence, charisma and passion.

> People with disabilities in many countries have proved themselves to be active partners in the development process

### self-help organisations in Bangladesh: the experience of ADD

ADD started its development programme with disabled people's organisations in Bangladesh in 1995. The programme initially started in one union (14 villages) of Mirpur Thana in the district of Kushtia with 6 self-help groups and has expanded to 9 unions (120 villages) with 48 grassroots self-help organisations. The long-term objective of the programme was to see democratic, representative and active federations of disabled people who are actively campaigning for the rights of ALL disabled people. These groups played a key role in building a disability movement in their communities. Disabled people are their own most powerful advocates and ADD works with them to gain the skills they need to become effective campaigners and to:

- build up disabled people's confidence in their own worth, abilities and rights
- set up self-help initiatives to improve their standards of living
- take control of their own lives; and campaign and advocate for equal rights and opportunities.

The self-help organisations that ADD supports in Kushtia differ from other disability programmes in the following ways:

### a rights-based approach

The conventional CBR medical model does not empower or encourage the participation of disabled people in the development process. However, in the rights based approach they have a vital role to play in creating a society where all disabled people have equal rights and equal opportunities. Over the past few years the people with disabilities in Kushtia district have been working for social mobilisation and have campaigned to:

- raise awareness throughout society to change negative attitudes and to establish equal rights of people with disabilities
- ensure the admission of children with disabilities in the existing schools
- gain access to the services of micro-finance institutions and commercial banks
- ensure inclusion in development programmes and access to local resources
- Secure an accessible transport system (self-help organisations campaigned for a reserved seat on public transport and care for wheelchair users)

Significantly, as awareness within the community increased, so did the respect and dignity of the people with disabilities. They started to be called by name instead of being referred to by their impairment – something that all disabled people long for!

### democratic, transparent and participatory approach

Democratic values are practised at every tier from the SHGs through to their federations. The members participate actively in the group meetings and their opinions are heard and acted upon. In this way all members are involved in the decision-making within the organisation. This democratic practice has become institutionalised.

Five union level federations have been formed through a free and fair election process when Executive Committees were elected for a two-year term. These Executive Committees submit progress reports and receipt and payment accounts to their membership and to ADD. This is an example of transparency. The decision-making processes of the federations are participatory and the responsibilities are decentralised.

### multiplying effect in forming Self-help Organisations

The self-help organisations have evolved with growing dimensions and have therefore had a multiplying, positive effect on the grassroots disability movement, in the following areas:

- **support for disabled people self-organisation:** Being influenced by their peers, the people with disabilities in the neighbouring villages and unions formed their own organisations. The federation leaders played the role of development workers in the facilitation and promotion of new groups.
- **cross-disability representative and gender focused:** The self-help organisations consist of 14 per cent people with visual impairment, 12 per cent people with hearing impairment, 10 per cent people with learning difficulties and 64 per cent people with physical impairment. 37 per cent of the membership are women with disabilities. The needs and issues of children and women with disabilities, people with hearing impairment and learning difficulties are being addressed.

- **solidarity for a National Disability Movement:** The SHGs in Kushtia District have formed networks with other national self-help organisations through visits and meetings. The aim of the self-help organisations is to form a national federation to strengthen the disability movement in the country to ensure their participation at every level of the society.
- **replication in NGO programmes:** Many NGOs (national and local) visited the self-help organisations in Kushtia and replicated their approach within their programmes. 10 NGOs in Kushtia and in other parts of Bangladesh have organised disabled people to start a process of empowerment. As well as forming self-help organisations they have begun to include people with disabilities in their mainstream programmes.
- **participation in planning, implementation and review:** The federations prepare monthly plans/budgets and implement the development activities for their members. They participate in the strategic and long term planning for ADD. They monitor their activities and review their progress against pre-set objectives and indicators. Through this process they build the managerial capacity to run their organisations independently. ADD plans to phase out its current function in Kushtia in 2001/02 when the self-help organisations have the capacity to operate independently.

## access to services available for the poor

The approach of self-help organisations empowers people with disabilities to access their rights. The self-help organisations in Kushtia have encouraged access in mainstream development activities of Non-Governmental Organisations (NGOs) and the Government. They have established their rights to the following services which are available in the community:

**Micro-Finance Institutions:** Micro-credit is an important and dominant tool of poverty alleviation in Bangladesh. The members of self-help organisations increasingly have access to micro-credit. 46 people with disabilities accessed credit of totalling Taka 235,000 (approx £3,405) from 14 NGOs and 3 Government programmes in 1999. In 1998, 73 self-help group members accessed credit of totalling Taka 100,000 (approx £1,449) from their own savings, they provided evidence that they were responsible loanees and capable of using credit effectively. Being sensitised by the success of people with disabilities, 33 NGOs in a national workshop committed to include them in their credit programmes.

**Education Institutions:** Education is a basic human right of all. The children with disabilities were often refused admittance to the schools. When the members of the self-help organisations realised that their right to education was being violated, they carried out an advocacy campaign targeting teachers of local schools and the Thana Education Office for inclusion of children with disabilities in the existing education institutions. As a result 133 children with disabilities have gained places at the local schools and colleges over the last 4 years. No schools (formal or non-formal) in Mirpur Thana now refuse places to children with disabilities. The schools are also offering opportunities for children with disabilities to participate in extracurricular activities, such as cultural programmes and sports events.

**Vocational Training Services:** The Department of Poultry, Livestock and Fisheries provides skill training in fishing, livestock and vegetable gardening. The self-help organisations have influenced them to include people with disabilities in their programmes.

**Services of Local Government:** People with disabilities were not priority in the local government poverty alleviation programmes. The federations at union level advocated for the inclusion of people with disabilities in their programme. The Union Council, Municipality and local Member of Parliament now consider self-help organisations as an active force. As a result 34 people with disabilities were included in the Vulnerable Group Fund/Development programme of the Government. The self-help organisations now have increased access to local resources.

**Access to Banking Services:** The self-help organisations save small amounts of money for their security in the future. They naturally prefer to keep the money in the Bank. However, the commercial banks refused to open bank accounts for the self-help organisations on the assumption that disabled people cannot operate a banking system properly. Following effective lobbying by disabled people the banks have now agreed to open bank accounts for disabled people. However, they do not provide credit to people with disabilities. This is just another issue the disabled people's organisations are fighting for in Kushtia.

### self-help organisations to support the community and vice-versa

People with disabilities are often seen as beneficiaries of a development programme. But they can also contribute to the development of the society if they are included. Some examples of support given by self-help organisations to the community are:

- One union federation in Kushtia has established three non-formal schools in response to the need identified by community members. 120 children who have previously not had the opportunity to attend school are now able to study.
- The self-help organisations help to mobilise other marginalised people within the community. For example, they formed six grassroots organisations of distressed women.
- When there was an outbreak of dengue fever in Bangladesh, self-help organisations attended awareness raising programmes on dengue prevention and management in the community.
- Representatives of the self-help organisations took part with government counterparts to observe the national polio immunisation day. The vaccination rate was very high in the areas where self-help organisations mobilised the children and parents. These programmes built credibility of the value of the self-help organisations within the community.
- The community members have also come forward to support the self-help organisations and the disability movement. Village support groups collaborate with the self-help organisations.

### looking ahead

The world scenario of disability is changing, there are both risks and opportunities. There is a hope that disabled people's organisations in many countries of the developing world will take spontaneous initiatives to end the social stigma of disability. The experience of grassroots disabled people's organisations indicates that we need a critical decade of determined effort to form self-help organisations from grassroots to the national level for the inclusion of disabled people in society. It is our professional responsibility to promote disabled peoples organisations and to support their initiatives for a society liberated from all barriers.

We, the disabled people, are weaving a net of active forces of disabled people from the local level at the grassroots to the international networks, campaigning for a world where we can participate fully at every level of the society as we so choose!

## Successful petitioning in Bangladesh

**On 23 November 2000, 5 disabled people left Kushtia on tricycles/ bicycles and began their 350 km journey to Dhaka to present a petition to the Prime Minister's office and to meet with the Speaker of Parliament to lobby for approval of the Disability Act, which has been dormant since 1995.**

**Along the route the cyclists held over 100 community meetings in the market places by the roadside. They assembled crowds together and collected over 1000 signatures in support of disabled people's right to legislative support. This petition was presented to the Prime Minister's Office on 3rd December -International Day of Disabled People. This was followed by a meeting with the Speaker of Parliament who assured the disabled cyclists that the legislation would be approved at the first sitting of Parliament in 2001.**

**On 4th April 2001 the legislation was approved by the Bangladesh Parliament - thanks to the five disabled cyclists from Kushtia, the Disability Movement in Bangladesh now has the long-awaited legislative support required to uphold their right to social parity and justice.**

*ADD Bangladesh*

Successful petitioning in Bangladesh. Thanks to these five cyclists awareness has been raised and the Disability Act has been approved.

# perspectives on disability and spirituality

**A Christian understanding of humanity recognises that everyone is created equally in the image of God. As a Christian organisation, we should reject any form of discrimination or exclusion. In the case of people with disabilities we have a duty to affirm their right to be considered and treated as equal to the rest of humanity. The two contributions that follow represent viewpoints that reflect this understanding, giving expression to the importance of observing and upholding the rights of people with disabilities.**

## 'taught by unexpected teachers'

**Hugh Nelson**

*L'Arche Community*

In L'Arche it is the outsider, the disabled, the vulnerable, the powerless and the degraded who reveal the face of God. In L'Arche we discover that we are all equal in the eyes of God; equally broken, equally loved. Our society does not deal with difference and with weakness well. We are all seeking to be strong, to be powerful and to be beautiful. This search is often an attempt to flee the unspoken and terrifying awareness of our vulnerability. In L'Arche we meet this vulnerability unhidden and undenied. People with learning disabilities have often suffered much and have been deeply wounded. They have known loss and rejection, and they may live their suffering very openly. In living alongside this suffering, we encounter our own wounds, acknowledged and unacknowledged.

In the experience of living Community and of making a commitment to a group of people, all as broken and as loved as each other, we discover something of the healing promised by Jesus in the Beatitudes (The Bible, Matthew V5). Not a nice, easy, uncomplicated healing, but healing rooted in our vulnerability and in the mess of life. In L'Arche we have discovered that those that society has rejected have much to teach us. Not about how to be strong, how to become better or how to be powerful, but about how to live and to love.

These lessons are taught by Anne, standing at the door of The Vine to greet you as if she has known you forever, although she has just met you for the first time; by Louise as she tells you that she missed you, although you have only been away for the afternoon; by Stephen, who faithfully remembers the birthdays of every Community member, as you open the card he sent. In L'Arche we learn together in the ordinary things of life, and we are taught by unexpected teachers.

# a version of the Beatitudes

### by a person with a disability

*reproduced by kind permission of The Christian*
*Ministries with Disabled Trust, New Zealand*

blessed

Blessed are you who take time to
listen to difficult speech,

for you help us to know that if we
persevere, we can be understood.

persevere

Blessed are you who walk with us in public
places and ignore the stares of strangers,
for in your companionship we find havens
of relaxation.

havens of relaxation

Blessed are you who never bid us to ‘Hurry up’,
and more blessed you who do not snatch our
tasks from our hands to do them for us, for
often we need time rather than help.

we need time rather than help

Blessed are you who stand behind us as
we enter new and untried ventures,

new and untried ventures

for our failures will be outweighed by the
times when we surprise ourselves and you.

Blessed are you who ask for our help,
for our greatest need is to be needed.

Blessed are you who help us with the
graciousness of Christ, who do not bruise
the reed or quench the flax, for often we
need the help we cannot ask for.

graciousness of Christ

Blessed are you when by all these things
you ensure that the thing that makes us
individuals is not our peculiar muscles, nor our
wounded nervous system, nor our difficulties
in learning. but in the God-given self which
no infirmity can confine.

blessed

Rejoice and be exceeding glad and know that
you have given us reassurance that could never
be spoken in words, for you deal with us as
Christ dealt with all His own children.

reassurance

**World Vision is a Christian relief and development agency which aims to provide the most effective ways of helping the world's poor build a better future for themselves and their children.**

**World Vision considers advocacy and education as key components of its role. Discussion papers are produced by the Policy Team of World Vision UK to promote debate on current development issues.**

**Cover photo:** Hard to believe that her mother had given up hope of ever seeing her daughter walk. Thanks to a physiotherapist Ma is able to walk on crutches and go to school. She has the same opportunity as her sister to fulfil her potential.

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World Vision is a registered charity no. 285908, a company limited by guarantee and registered in England no. 1675552.

Registered office as above.

all things being equal: perspectives on disability and development   Autumn 2001

World Vision

# all things being equal

## perspectives on disability and development

# list of acronyms

| | |
|---|---|
| **AusAID** | Austrailian Agency for International Development |
| **ADD** | Action on Disability and Development |
| **CBR** | Community Based Rehabilitation |
| **CIED** | Child Inclusive Education Development Project |
| **CRC** | Convention on the Rights of the Child (1989) |
| **DAA** | Disability Awareness in Action |
| **DEC UK** | UK Disasters Emergency Committee |
| **DFID** | Department for International Development |
| **DPO** | Disabled People's Organisation |
| **ESCAP** | Economic and Social Commission for Asia and Pacific |
| **IDDC** | International Disability and Development Consortium |
| **INGO** | International Non-Governmental Organisation |
| **NGO** | Non-Governmental Organisation |
| **NUDIPU** | The National Union of Disabled Persons of Uganda |
| **PWD** | People/Persons with disabilities |
| **SCF** | Save the Children Fund |
| **SHG** | Self-help Group |
| **UN** | United Nations |
| **UNESCO** | United Nations Educational, Scientific and Cultural Organisation |
| **UNICEF** | United Nations Children's Fund |
| **VSO** | Voluntary Service Overseas |
| **WHO** | World Health Organisation |

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