



THE INVISIBLE PEOPLE

A practical guide for journalists
on how to include persons with disabilities

The Secretariat *of the*
African Decade
of Persons with Disabilities

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"The most effective way to mobilize public support for human rights is through the media. The media can educate the public about their rights, and act as an effective watchdog against human rights abusers."

- Journalists for Human Rights, JHR

INTRODUCTION

- How can journalism help?

Persons with disabilities are not seen regularly in the media, and are rarely portrayed as persons with opinions on news and topical issues. When they are interviewed it is mostly on disability issues. Or they will be talked about with pity, or with astonishment because they have managed to do something brave 'in spite' of their disabilities. The disability is almost always on centre stage when an individual that has a disability appears in the public media.

As professional communicators you are in a unique position to shape the public image of persons with disabilities. The words and images you use can create either a straightforward, positive view of persons with disabilities or an insensitive portrayal that reinforces common myths and is a form of discrimination.

Why is it important for persons with disabilities to be in the media?, you may ask. There are several reasons. For one thing, it can help the some 80 million persons with disabilities in Africa that are often discriminated against and excluded from schools, work opportunities and health services, to become more visible in their societies. As long as this large group of people are invisible, the inequalities experienced by them will remain largely unknown to the general public. The positive changes that do take place on our continent with regards to persons with disabilities also remain unknown. This lack of knowledge helps to perpetuate discrimination and exclusion of Africans with disabilities. Also, persons with disabilities themselves will not get the information that they need about services available to them and improvements in national policies and programs. In developing countries, being made aware of services and opportunities may be an important first step to actively take part in society. Media initiatives and individual journalists can help people feel less isolated, while at the same time challenge negative stereotypes in communities.

In this manual we discuss key disability issues, key messages and principles for journalists wanting to support the human rights of Africans with disabilities. The manual also deals with terminology. It is about using words that do not offend people and that puts the person rather than the disability first.

Persons with disabilities should be interviewed on topical issues in daily news reporting, and be allowed to have their own voice. All it takes is for a journalist to seek out that person - or welcome persons with disabilities to call the newsroom to offer their services and ideas. After this training, we hope that you will feel more comfortable with disability issues and how to communicate with a person that has a disability. Our wish is that this will be reflected in the work that you do as a journalist in Africa. We encourage you to keep this manual for future reference.

"The modern day media plays an important role not only in reflecting public attitudes and values regarding disability, but also in shaping them."

- Gold and Auslander, *Disability and Society*, 1999.

BACKGROUND

Rising numbers

A disability is a condition caused by accident, trauma, genetics or disease which may limit a person's mobility, hearing, vision, speech or mental functions. Some people have one or more disabilities.

Every day in Africa, many people are disabled by malnutrition and disease, environmental hazards, natural disasters, traffic and industrial accidents, civil conflict and war. In Angola alone, at least 100 000 men, women and children are disabled as a result of explosives such as landmines. The World Bank estimates that in countries emerging from conflict, as many as 25% of the population are clinically depressed. At minimum, people with disabilities comprise 10% of any population—in Africa, therefore, the total would be around 60-80 million. There are some 600 million persons with disabilities worldwide. Taking into consideration the impact on families, the lives and livelihood of more than one billion people in the world, or about 25% of the population, are affected.

As a result of improvements in child survival, the numbers of children surviving with disabilities are increasing and as more Africans survive to older age, the numbers of elderly people with disabilities are rising.

The disability movement

Disabled people's organizations (DPOs) are NGOs that are established, governed, and managed by persons with disabilities. They represent the voice and interests of individuals with disabilities at the international, national and local community levels. There are two types of DPOs: those organizations formed to represent all types of disabilities, such as Disabled People International; and those that focus on one type of disability, such as the World Blind Union. A distinction is sometimes made between those organisations that work *for* the rights of persons with disabilities, but that are not necessarily managed by persons with disabilities, and the organisations that are run entirely by persons with disabilities, labelled organisations *of* persons with disabilities.

The disability movement started in North America and Europe in the 1970s, largely led by Viet Nam War veterans and young human rights activists with disabilities. It later expanded to Africa, Latin America, and Asia in the 1980s. The establishment of Disabled People International (DPI) in 1980 and its receipt of Economic and Social Council (ECOSOC) consultative status in the United Nations in 1983 marked the internationalization of the disability movement.

Historically, DPOs have advocated strongly and successfully for the equal rights of persons with disabilities in North America and Western Europe. National, local, and institutional policies have changed, forcing these societies to be more inclusive, accessible, and accepting of persons with disabilities. The outcome has been a marked shift in the scope and type of services, employment, education, and transportation. For example, a 2002 investigation of the economic status of persons with disabilities found that 37% of the population of persons with disabilities in Canada and 49% in the United States are employed. A study made in Sweden in 2004 showed that 56% of all adult persons with disabilities were employed. At the same time there is an unemployment rate of 80% internationally among persons with disabilities, according to a 2003 study by the International Labour Organisation. South Africa found an 88% unemployment rate among disabled persons in 2002. In many of the poorest countries in the world the level is much higher than that, with persons with disabilities being almost completely excluded from opportunities to work.

In Africa there are several different levels of DPOs. There are local or district DPOs that may cover only a small area of one country. Regional DPOs can be either disability specific, e.g. only focus on issues for the blind, or have a cross-disability scope. There are also national DPOs, serving whole countries, which in turn are members of national federations. A national federation is an umbrella organisation for all national DPOs in a specific country. When you want to communicate with DPOs in your country, the national federation is a good place to start. On the next level you will find continental DPOs that are disability specific, such as the African Union of the Blind and the African Deaf Union. On the continental level there are also regional cross-disability DPOs: CAFOD (Central African Federation of the Disabled), NAFOD (North African Federation of the Disabled), EAFOD (East African Federation of the Disabled), WAFOD (West African Federation of the Disabled) and SAFOD (Southern Africa Federation of the Disabled). Finally, there is PAFOD, the Pan African Federation of the Disabled, which is the pan African cross-disability organisation that covers the whole continent and deals with all types of disabilities.

Disability as a human rights issue

Persons with disabilities have suffered from a relative “invisibility”, and have tended to be viewed as “objects” of protection, treatment and assistance rather than subjects of rights. As a result of this approach, persons with disabilities have been excluded from mainstream society, and provided with sheltered workshops and separate housing and transportation on the assumption that they were incapable of coping with society at large. They have been denied equal access to basic rights and fundamental freedoms (e.g. health care, employment, education, voting and participation in cultural activities) that most people take for granted.

The traditional way of addressing disability has been either through medical or charitable approaches. The charity model portrays disability as a personal tragedy with persons with disabilities being objects of pity, and referred to as “crippled”, “crazy” or “idiot”. This model long entrenched society’s view of people with disabilities as dependent and in need of protection, often also leading to a belief that they needed to be hidden from society and institutionalised. The medical model created improvements in the capacity of society to prevent the causes of disabilities, and led to the development of welfare services. However, this was done at a high cost for persons with disabilities, as they were perceived as “sick” and in need to be controlled by medical professionals. These models have both had negative effects on the self-esteem of many persons with disabilities, and they created a lot of negative attitudes towards them.

A dramatic shift in perspective has been taking place over the past two decades, and persons with disabilities have started to be viewed as holders of rights. This process is slow and uneven, but it is taking place all over the world. The rights-based approach to disability essentially means viewing persons with disabilities as subjects of the law. Its final aim is to empower disabled persons, and to ensure their active participation in political, economic, social, and cultural life.

It is now being recognised that a person with a disability has a right to be included and to participate in society as a full member. He or she is not to be treated as a passive target for help and charity. Consequently, a policy shift is taking place in organisations and governments. There is a move from disability specific policies and programs that are solely related to persons with disabilities, towards a mainstreamed approach. This means that disability issues are being addressed within the more general policies, such as poverty reduction or infrastructure.

"A healthy society is one that takes care of all its members, and gives them a chance to participate in decisions that affect their lives."

- Kofi Annan, Secretary General of the United Nations, 2000

This shift to a human rights perspective has been endorsed at the level of the United Nations, and is reflected in several developments which have taken place internationally since the proclamation by the General Assembly of the year 1981 as the "International Year of the Disabled" under the slogan "Full Participation and Equality". In 1982, the General Assembly adopted the World Programme of Action concerning Disabled Persons, which set the guidelines for a world strategy to promote "equality" and "full participation" by persons with disabilities in social life and development. As a follow-up to the World Programme of Action, the General Assembly adopted a resolution in 1993 entitled Standard Rules on the Equalization of Opportunities for People with Disabilities. The Standard Rules explicitly take the International Bill of Human Rights as their foundation. Although the UN standard rules are not legally binding, they represent a moral and political commitment of governments of member states to ensure equal opportunities for all their citizens. In the end of 2006, the General Assembly of the United Nations adopted the worlds first-ever convention on the rights of persons with disabilities.

A new human rights convention

The development of the first-ever convention on the rights of persons with disabilities reflects the growing international acknowledgement of *disability rights* as *human rights*. Until now, the rights of persons with disabilities have only been covered implicitly by existing human rights conventions – simply because they apply to all human beings. The convention on the Rights of the Child has been the only one that explicitly mentions children with disabilities. Having only legally non-binding instruments has often lead to a situation where persons with disabilities continue to be treated within a social welfare approach, and not as rights holders.

The Ad-Hoc Committee on a *Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities* met for the first time in 2002. More than 400 delegates and disability advocates have attended eight sessions of the Committee at the United Nations in New York. The Convention is moving beyond the traditional concept of access to the physical environment, to broader issues of equal access, social opportunities, health, education, employment, political, economic and social development, and elimination of legal and social barriers to equal participation. Governments that ratify it will be legally bound to treat persons with disabilities not just as victims or a minority, but as subjects to the law with clearly defined rights. The ratification process started in March 2007.

"Nothing about us without us"

This slogan by Disabled Peoples' International is used by disability activists all over the world. It has, for example, informed their message to governments in the UN process of elaborating the convention on the rights of disabled people: that in doing this they must listen to the voice of disabled people.

GOALS

As a media professional you are in a position to shape the public image of persons with disabilities. After this training we hope that you will work together with us towards these goals:

1. To increase awareness about the situation of disabled people in Africa among the general public in Africa.
2. To promote positive attitudes towards children, youth, women and men with disabilities and support the human rights of persons with disabilities.
3. To include and interview persons with disabilities in news and topical reporting, portraying them as part of the general public.

KEY MESSAGES

To work towards the goals above, you may want to focus on the following key messages. These messages will be adapted to local situations and specific circumstances, and should be seen as steering tools or a guide towards developing specific messages or stories:

1. An estimated 60-80 million persons with disabilities live in Africa. The vast majority of them live in poverty and are excluded from opportunities to work and study.
2. The inclusion of Africans with disabilities needs to be enhanced in all sectors of community life. Persons with disabilities are both willing and able to contribute to the development of their societies.
3. Persons with disabilities are part of all levels of society and have opinions, experience and knowledge about all sorts of issues. They are not only interested in disability related matters.

"It is if we have no opinions or knowledge about political or news issues, only about strictly disability related issues."

- Fadila Lagadien, Member of the board of The South African Broadcasting Corporation

KEY PRINCIPLES

In order to support the human rights of persons with disabilities through your work, we suggest that you follow a set of key principles, listed in this section. These principles are developed as a toolkit on how persons with disabilities would like to be portrayed or approached by the media:

Put the person at centre stage, not the disability

For each person in every country, there are some things they cannot do – but far more importantly, there are also things they can do. That is true for all of us. When you interview a person that does not have a disability, you do not automatically ask yourself what that person is unable to do, although there are things, different things for each person, that he or she finds difficult or impossible to do. When you interview a person with a disability, the most interesting thing about that person is surely not the disability. Far more interesting is to listen to his or her opinions, ideas and knowledge. Show an interest in the potential that all people have. Nobody wants to be defined after their inabilities. Portray persons with disabilities as you would anyone else, with both human strengths and weaknesses.

Focus on abilities. Do not focus on disabilities, unless they are crucial to a story. Avoid tear-jerking human interest stories about incurable diseases, congenital impairments, or severe injury. If you want to report on disability issues, focus instead on issues that affect the quality of life for those same individuals, such as accessible transportation, housing, affordable health care, employment opportunities, and discrimination. Do not refer to an individual with a disability as *the disabled* simply to save space or accommodate design layouts. This is a dehumanising term that puts the disability rather than the person first.

” - Are you disabled? – No, I’m Daisy.”

- A girl with Down’s Syndrome was playing with a boy on the beach. Their conversation was quoted in a report for the UN General Assembly Special Session on Children, 2001.

Show persons with disabilities as active in society

Portraying persons with disabilities actively participating in society, interacting with non-disabled people in social and work environments helps break down barriers and open lines of communications. Try to show persons with disabilities as providers of expertise, services and assistance to break through the stereotype of presenting persons with disabilities only as recipients of charity, services and goodwill. Show or describe individuals with disabilities in the same everyday situations where you would describe other people.

Picture persons with disabilities as part of the general public

Most persons with disabilities want to take part in and contribute to their communities just like everyone else. Since at least percent of the population has some kind of disability, roughly ten percent of the people we see or hear in the media should also have disabilities, if there were equal representation. This is of course not the case. How come we hardly ever see somebody in a wheelchair comment on the election results, or a blind person discuss the school curriculum in the media? Is it because persons with disabilities never have opinions about topical issues or politics – or is it because we never think about asking them to participate? Make an effort to seek out persons with disabilities when you report on issues that are important in your community. Listen to their opinions. Just because a person has a disability does not mean that he or she is only interested in disability issues. If you do not know how to find or contact a disabled person where you work, call a local Disabled Persons' Organisation and ask for assistance.

Let people have their own voice

Just like you would want to hear a woman tell the story of how it feels to be pregnant, or listen to a black person explain how discriminated they were during apartheid in South Africa – would it not also be interesting to know more about the experiences of disabled people? Let them have their own voices, for they tell their stories best. It is, as always, perfectly all right to edit for the sake of clarity if necessary. But let everybody have their own voice and use their own words.

When talking with a person with a disability, speak directly to that person rather than to a companion or interpreter. Conduct interviews in a way that emphasises abilities and individual qualities. Address people who have disabilities by their first names only when calling everyone else present by their first name. If you offer assistance to the person you are interviewing, wait until the offer is accepted before acting. Then listen to or ask for instructions on how you can help.

Avoid common stereotypes: the superhero and the victim

Do not portray successful people with disabilities as superhuman or heroes. Even though the public may admire super-achievers, the fact that people with disabilities are often portrayed only as superstars that have done something “despite” their disabilities raises false expectations that all people with disabilities should achieve this level. Also, do not imply disease when discussing disabilities that result from a prior disease episode. People who had polio and experienced after effects have post-polio syndrome. They are not currently experiencing the disease. Do not imply disease with people whose disability has resulted from anatomical or physiological damage (e.g., person with spina bifida or cerebral palsy). Reference to disease associated with a disability is acceptable only with chronic diseases, such as arthritis, Parkinson's disease, or multiple sclerosis. People with disabilities should never be referred to as patients or cases unless their relationship with their doctor is under discussion. The superhero and the victim are common stereotypes reproduced by the media that help to perpetuate misconceptions about persons living ordinary lives among the rest of us with some form of disability.

Support the human rights approach

Do not write or speak about disability in terms of charity. Do not talk about disability with pity. Do not treat disability issues as strictly medical issues, or portray disability as a disease. If you make an effort to treat persons with disabilities as citizens with a right to participate in all sectors of society, you support the human rights model of disability. It is all about inclusion and respect.

Work with journalists with disabilities

Unless persons with disabilities are able to be the makers of own images, their lives will constantly be depicted on the basis of the assumptions others hold of who they are. In a participatory democracy, media should be representative of all.

Communicate with disability organisations

Media professionals can be a lot more proactive when it comes to communicating with disability groups. If persons with disabilities are not contacting you or bringing their ideas and opinions to your attention, you can pick up the phone and call a local Disabled Persons' Organisation and ask for an interview or a comment. After all, you would not just sit at your desk and wait for the world to contact you and tell you about general news issues. In the same vein, you can take the first step to improve the inclusion of persons with disabilities in your newspaper or programme. If you build a relationship with an organisation, it may generate a lot of good ideas and contacts that will benefit you in your future work.

Persons with disabilities are not only interested in disability issues

How many times have you seen somebody who has a disability in a television news studio, commenting on the latest political developments or election results in your country? If we see a person that uses a wheelchair in a television studio, we automatically assume that they are discussing disability related issues. This common automatic reaction can be changed by improving the representation of persons with disabilities in mainstream media reporting. There are persons with disabilities in all sectors of society, and in all sorts of professions. Do not miss out on their knowledge and expertise.

Be honest

Tackle disability with honesty – say ‘I feel uncomfortable, and I do not know what words to use now’. Or use the terminology guide in this manual and say that ‘persons with disabilities’ is the term to use in Africa, not ‘handicapped’ or ‘infirm’, which implies disease.

Integration between disabled and non-disabled is a relatively new field. When you tackle subjects like this, have the honesty to admit that you do not really know what is going on, because it has not happened much in your country. It is all right to be insecure, and want to learn. Ask the person that you are interviewing about things that you do not understand. Ask the person if he or she needs assistance, and wait for their response before doing something for them.

“I think many times honesty gets sidelined, in order to be politically correct or just to hide.”

- Malcolm Black, a dancer in Remix Dance Project, South Africa.



KEY DISABILITY ISSUES

We wish to see persons with disabilities interviewed not only about disability issues, but on everything from music to politics. However, there are disability specific issues that are important to discuss in the media too, because they are important human rights issues affecting many people. We list issues in this section that currently are on top of the disability movement's agenda. All of them should of course be viewed from a human rights perspective.

Accessibility

Accessible housing, transportation and information affect the quality of life for individuals with disabilities. Persons who are deaf cannot access radio messages, and television messages are often difficult to understand for those who are blind. This, combined with low literacy rates among persons with disabilities in poor countries, present real challenges to public information outreach such as important security messages or HIV and AIDS education. It may be difficult to find hotels that are accessible for persons using wheelchairs when they go on holiday, as there may be no lift or a lift that is too small for a wheelchair. Inaccessible hospitals and other health care facilities are common and create serious problems. The same goes for offices that are inaccessible for persons with physical disabilities. These buildings are barriers to employment opportunities for these individuals.

Often, the remedy for accessibility problems are simple and inexpensive, such as a ramp outside of the hospital or office building, or public information in multiple formats. Accessibility requirements should be included in the design and construction of the physical environment from the beginning of the planning process. Incorporating a ramp into a building design at its initial construction may not be very costly, certainly as compared with the overall cost of the building, but retrofitting buildings with ramps will be much more expensive. As a journalist you can monitor that new buildings in your area are accessible, and report when they are not. This may increase the awareness about this important issue among politicians, architects, construction engineers and others who are professionally involved in the design and construction of the physical environment, and hopefully lead to an improvement that will benefit many in your country.

The disabling environment

The "invisibility and isolation" of people with disabilities are caused by stigma, discrimination, myths, misconceptions, and ignorance. *Disability* is frequently defined as *the outcome of the interaction between a person with a health condition and the negative barriers of the environment, including attitudes and beliefs*. The reality is that a physical condition only becomes disabling when the person interacts with the environment. For instance, a person in the United Kingdom with poor vision would receive glasses and not be considered or feel himself/herself to be a disabled person. However, a person in rural Africa with the same poor vision would not have access to ophthalmic care, would probably not do well at school, and would become a disabled person when interacting with the environment. By informing the public, you as a journalist can help to break down some of the barriers that keep persons with disabilities excluded.

Poverty

Poverty and disability are interrelated. Poor people are more likely to have a disability because of the conditions in which they live. Disability is likely to make people poorer because of limited work and education opportunities and discrimination.

Despite the fact that the World Bank estimates that some 80% of persons with disabilities in Africa are poor, disability has generally not been taken into consideration in the national Poverty Reduction Strategy Papers (PRSPs) that guide national poverty reduction programs. Disability is not explicitly mentioned in any of the eight Millennium Development Goals (MDGs) either, nor in the 18 targets set out to achieve these goals or the 48 indicators for monitoring their progress. The Disability Knowledge and Research Programme, funded by the UK Department for International Development, have stated that all of the eight MDGs are clearly linked to disability, and that persons with disabilities must be made part of the process to reach the goals. They have said that disability and poverty are mutually reinforcing and that disabled people represent a large proportion of the poor.

"Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 or to give every girl and boy the chance to achieve a primary education by the same date – goals agreed to by more than 180 world leaders at the UN Millennium Summit in September 2000."

- James Wolfensohn, Former president of the World Bank

Mainstreaming

One of the working focuses of the disability movement has become to mainstream disability, i.e. to get disability and persons with disabilities included in the existing development community. It is about getting governments and development organisations to include disability into policies and programs, and to invite persons with disabilities to participate in the development of these policies and programs. The disability movement does not want separate, exclusionary processes, keeping them out of the mainstream societies. It simply does not make sense to exclude around 10 percent of the people in any African country from regular development programs or health care policies.

Health care

A consequence of living in poverty with a disability is inadequate access to health services, resulting frequently in serious secondary conditions and general deterioration of the quality of life. Additional complications are caused by lack of knowledge about health conditions. Information on health care is often not provided in accessible formats and disabled persons are not targeted in health education. Furthermore, health workers may discriminate against them. Disabled women often complain that doctors deny them access to reproductive health services. Some persons with disabilities have specific medical needs. Meeting such needs is a prerequisite for achieving equality and full participation in society.

HIV and AIDS

Persons with disabilities are at equal or higher risk of HIV infection, compared with people without disabilities, it has been concluded by Yale University. Yet, African governments and policy makers have rarely considered the needs of disabled persons when formulating their HIV and AIDS strategies, and individuals with disabilities are mostly absent from consultation processes. Many major HIV and AIDS donors, aid agencies and specialised NGOs do not consider the particular needs of persons with disabilities in their programmes. Not even organisations of and for disabled persons always recognise that their members are at risk.

Individuals who have a disability are often assumed not to be sexually active, and therefore not at risk of contracting HIV. They are even sent away from testing facilities by doctors saying 'you are disabled, you could not possibly be HIV positive'. However, studies have shown that persons with disabilities are more likely to have several sexual partners in a series of unstable relationships than their non-disabled peers, because they are less likely to marry. Disabled men and women are also more likely to be victims of sexual abuse and rape. Sex education programs for those with disabilities are rare. Access to general healthcare services is also poor for persons with disabilities for a variety of reasons, including social and economical obstacles and problems to physically access the health facilities. In addition to this, disabled persons living with HIV in Africa often face multiple stigmas from being disabled, poor *and* HIV-positive.



"I have never seen anyone with a disability included in a HIV/AIDS information poster."

- Dr Nora Groce, Yale University

Education

Universal primary education is unobtainable without the inclusion of disabled children. 98 per cent of children with disabilities in the world receive no formal education according to UNICEF. Even if the school is physically accessible, many children with disabilities remain excluded. Parents may fear that the child will not cope or that allowing the child to leave the home will stigmatise the whole family. They may consider that investment in a disabled child is not worthwhile. Those children who do get education often receive inferior treatment, have low expectations of themselves and from others and do not get the support they need in order to participate on an equal basis.

Employment

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations 1994) state that “Laws and regulations on employment should not discriminate against persons with disabilities or raise obstacles to their employment. States should recognize the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment.” Yet, in many countries in Africa it is very difficult for persons with disabilities to find work. By showing or describing persons with disabilities in professional positions, you may contribute to a more inclusive labour market by making people used to seeing persons with disabilities in different professions.

Culture

There are integrated dance companies that bring together performers with physical disabilities and those without and there are successful African musicians that are blind. Artists with disabilities in all cultural sectors enrich their communities and they address the issue of accessibility to culture, arguing that everybody can be full participants in the cultural lives of their countries. States should ensure that persons with disabilities have the opportunity to use their creative, artistic and intellectual potential. Theatres, museums, cinemas and libraries should also be accessible to persons with disabilities. Culture is an important social sector and part of life, where local artforms vary from dance, music, theatre, painting and sculpture to puppetry and story-telling. Through promoting participation in and access to culture, we can all invite persons with disabilities into community life and make many feel less isolated and invisible.

Sport

Persons with disabilities should have equal opportunities for recreational activities and sports. This means that sports facilities should be accessible to persons with disabilities. Services should be offered to all, taking into account the special needs of persons with disabilities. Often all it takes is to invite individuals with disabilities to join in. In so doing we can all promote social inclusion, participation and visibility. In preparation for the International Year of Sport and Physical Education, the United Nations identified that sport can and should play a role in achieving the Millennium Development Goals (MDG). They said, for example, that goal number 1 on eradicating extreme poverty and hunger can be aided through sport because the sports industry creates employment opportunities. The United Nations also stated that sports promotes gender equality and empowers women, building confidence and social integration (Goal 3). By promoting social inclusion for those who are traditionally marginalised, sport can also bring people with disabilities into the process of achieving the MDGs. The media could do a lot more than they are doing in this regard, by showing persons with disabilities who actively take part in daily sports events. Not only the Paralympics.

“People in every nation love sport. Its values – fitness, fair play, teamwork, the pursuit of excellence – are universal. It can be a powerful force for good in the lives of people devastated by war or poverty – especially children.”

- Kofi Annan, United Nations Secretary General

Children with disabilities

Children with disabilities require attention to ensure prevention, early intervention, timely rehabilitation, access to education, recreation, and social integration leading to their full inclusion in society as children and then later as adults. Disabled children need support and opportunities to be integrated into mainstream society. The Convention on the Rights of the Child is a guiding framework; it specifies children's rights to protection from all forms of economic and sexual exploitation, violence, armed conflict, and discrimination based on disability, gender, religion, or ethnicity. It is unjust for disabled children to be excluded from growing up with other children in the normal course of life.

Women with disabilities

Disabled women, particularly those from poor rural villages, often have very little control over their lives and face discrimination and abuse not only because of gender but also due to their disability. Women with disabilities feel that they face a triple disadvantage as women, as disabled, and as women with disabilities. Attitudes toward women with disabilities and the expectations of their roles in society in many cases significantly limit their lifestyle choices in issues including family, motherhood, education, employment, and health care, and influence the way disabled women perceive themselves. Cultural and social structures restrict women's mobility, freedom of speech, and basic human rights. Disabled women, particularly those in rural communities, often have no or very limited freedom or independence. It cannot be overstated how necessary it is to pay significant attention to addressing the needs of disabled women.

"Why aren't there any children in wheelchairs on TV? If there were, people would stop thinking about us as strange and would know the issues."

- Gareth Burton, 12 years old, Northern Ireland

"Adults are uncomfortable around me and seldom speak directly to me. They'll stare, and then quickly look away. Some will ask questions about my disability and always respond in the same way, with sympathy and pity."

- Rezaan Achmat, 12 years old, South Africa

The Convention

The General Assembly has adopted the first-ever convention on the rights of persons with disabilities at the United Nations. The convention, once it is ratified, will force countries to look at their own legislation from a disability point of view. In so doing, a separate convention can enhance and enforce mainstreaming of disability into national legislation.

Implementation is the main concern now. Who will make governments accountable in the process of implementing the convention? This is possibly an even bigger concern in Africa than in other parts of the world, because of the lack of capacity and funds at the national level. Many Africans worry that the convention will be just another document not put into practice. The money issue is the predominant concern. Putting the provisions of the convention into practice will be costly. Some have cautioned that lack of money may hinder states to meet even the most urgent obligations. All countries will face costs, but it will be hardest for developing countries.

“There is no point in societies creating an environment in which persons with disabilities are unable to contribute, and then criticising them for not doing so.”

- Ambassador Don MacKay, chairman of the Ad-Hoc Committee on a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities.

“Everyone has to make an effort to understand each other.”

- Amadou and Mariam, stars on the international music scene, nicknamed ‘The blind couple from Mali’.

WORDS MATTER

- A terminology guide

When writing or speaking about persons with disabilities it is important to consider the impact that words may have both on the general public and on the disability community. Non-disabled people often feel intimidated about how to address persons with disabilities for fear of saying the wrong thing.

As a general rule, you will never offend or confuse by using "person-first" language. Persons with disabilities prefer to be called just that, persons with disabilities. An individual is not "an epileptic", but rather "a person with epilepsy". Putting the person's disability before their name, e.g., "a blind woman", instead of "a woman who is blind", is to put the disability first. Similarly, when speaking of the whole population segment, it is better to say "persons with disabilities" than "disabled people" or, worse yet, "the disabled." These terms are irritating to many individuals; a disabled car, after all, is one that will not work. A person with a disability has many abilities. Never say "a victim of" or "suffers from". Disability is not a disease.

Some other terms are simply not acceptable in the 21st century, including *crippled, lame, retarded, deaf and dumb, invalid, deformed, and wheelchair-bound*. That last term is particularly ironic. For a person who cannot walk, a wheelchair is in fact a liberating mobility tool, not something that binds. Therefore, write "uses a wheelchair" instead of "is confined to a wheelchair" or "is wheelchair bound". The term *impairment* should be used sparingly and only under exceptional circumstances. "Handicap" is defined in the Webster's Ninth New Collegiate Dictionary as "to put at a disadvantage". This term refers to a physical or attitudinal constraint imposed upon a person, regardless of whether that person has a disability.

The media has a role in helping to 'mainstream' or 'normalise' disability by depicting it in a fair way. This, in turn, will make people more comfortable with the appropriate language to use. However, if you try to be too precious or politically correct and get overly sensitive to every word, it will probably stop you from writing or saying anything about disability. Just take care to use language that does not reinforce negative stereotypes.

Also, relax when you talk to a person with a disability. It is perfectly ok to use everyday phrases such as "see you later", even when you are talking to a person that is blind. Address individuals with disabilities in the same way as you would everybody else. Communicate directly to the person, even if accompanied by an interpreter or companion.

The following section is a guide on how to describe individuals with certain disabilities. These guidelines reflect input from over a hundred disability organisations, although opinions may differ on some terms. We have borrowed information for this section from The Life Span Institute.

"Lack of awareness is largely responsible for the marginalization and exclusion of persons with disabilities from the social, development and political spheres."

- from the Kenya National Disability Policy.

Autism

Autism is a mental disorder originating in infancy that is characterized by absorption in self-centred subjective mental activity, especially when accompanied by marked withdrawal from reality, repetitive behaviour, and language dysfunction. Do not say autistic. Say person with autism.

Blind

Blind describes a condition in which a person has loss of vision for ordinary life purposes. Visually impaired is the generic term used by some individuals to refer to all degrees of vision loss. Say boy who is blind, girl who is visually impaired, or man who has low vision.

Brain injury

Brain injury describes a condition where there is long-term or temporary disruption in brain function resulting from injury to the brain. Difficulties with cognitive, physical, emotional, and/or social functioning may occur. Do not say brain damaged. Say person with a brain injury, woman who has sustained brain injury, or boy with an acquired brain injury.

Deaf

Deaf refers to a profound degree of hearing loss that prevents understanding speech through the ear. Hearing impaired or hearing loss are generic terms used to indicate any degree of hearing loss—from mild to profound. These terms include people who are hard of hearing and deaf. However, some individuals completely reject the term hearing impaired. They prefer to use deaf or hard of hearing. Hard of hearing refers to a mild to moderate hearing loss that may or may not be corrected with amplification. Say woman who is deaf, boy who is hard of hearing, individuals with hearing losses, people who are deaf or hard of hearing.

Developmental disability

Developmental disability is any mental and/or physical disability starting before the age of 22 and continuing indefinitely. It limits one or more major life activities such as self-care, language, learning, mobility, self-direction, independent living, and economic self-sufficiency. This term includes individuals with mental retardation, cerebral palsy, autism, epilepsy and other seizure disorders, sensory impairments, congenital disabilities, traumatic injuries, or conditions caused by disease (such as polio and muscular dystrophy). It may also be the result of multiple disabilities. Say person with a developmental disability.

Disability

Disability is a general term used for a functional limitation that interferes with a person's ability, for example, to walk, lift, heal, or learn. It may refer to a physical, sensory, or mental condition. Do not refer to people with disabilities as the handicapped, handicapped persons, abnormal or special. Handicap can be used when citing laws and situations, but should never be used to describe a person or disability. Use disability as a descriptive noun or adjective, such as person living with AIDS, woman who is blind or man with a disability.

Disfigurement

Disfigurement refers to physical changes caused by burns, trauma, disease or congenital conditions. Do not say burn victim. Say burn survivor, adult with burns or child with burns.

Down Syndrome

Down syndrome describes a chromosome disorder that usually causes a delay in physical, intellectual, and language development. Mongol, Mongoloid, and Downs child/person are not accepted. Say person with Down syndrome.

HIV & AIDS

HIV is an infectious disease resulting in the loss of the body's ability to ward off infections. A positive test for HIV can occur without symptoms of the illnesses that usually develop up to 10 years later, when a HIV positive person has developed AIDS, including tuberculosis, recurring pneumonia, cancer, recurrent vaginal yeast infections, intestinal ailments, chronic weakness and fever, and profound weight loss. Don't say AIDS victim. Say people living with HIV, persons who are HIV positive, people with AIDS or living with AIDS.

Learning disability

Learning disability describes a permanent condition that affects the way individuals take in, retain, and express information. Some groups prefer specific learning disability, because it emphasizes that only certain learning processes are affected. Do not say slow learner, retarded, etc., which are different from learning disabilities. Say person with a learning disability.

Mental disability

The Federal Rehabilitation Act (Section 504) in the United States lists four categories under mental disability: psychiatric disability, retardation, learning disability, or cognitive impairment as acceptable terms. Mental disability is generally the preferred collective term. Always precede these terms with, "person with..."

Non-disabled

Non-disabled is the appropriate term for people without disabilities, when separating them from individuals with disabilities. *Normal, able-bodied, temporarily able-bodied, healthy, or whole* are inappropriate.

Post-polio syndrome

Post-polio syndrome is a condition that affects persons who have had poliomyelitis (polio) long after recovery from the disease and that is characterized by muscle weakness, joint and muscle pain, and fatigue. Do not use polio victim. Say person with post-polio syndrome.

Psychiatric disability

Psychotic, schizophrenic, neurotic, and other specific terms should be used only in proper clinical context and should be checked carefully for medical and legal accuracy. Words such as crazy, maniac, lunatic, demented, schizo, and psycho are offensive and should never be applied to people with mental health problems or anyone else. Acceptable terms are persons with psychiatric disabilities, psychiatric illnesses, emotional disorders, or mental disorders.

Speech disorder

Speech disorder is a condition in which a person has limited or difficult speech patterns. Do not use mute or dumb. Use child who has a speech disorder. For a person with no verbal speech capability, say woman without speech.

Spinal cord injury

Spinal cord injury describes a condition in which there has been permanent damage to the spinal cord. Quadriplegia denotes substantial or significant loss of function in all four extremities. Paraplegia refers to substantial or significant loss of function in the lower part of the body only. Say man with paraplegia, woman who is paralyzed, or person with a spinal cord injury.

Stroke

Stroke is caused by interruption of blood to the brain. Hemiplegia (paralysis on one side) may result. Stroke survivor or person who has had a stroke is preferred over stroke victim.

PRESS COVERAGE EXAMPLES

A group of adults with different disabilities has begun a workshop to produce and sell jewellery. All of the workers need the income from sales to support themselves and family members, but there is not much business right now. The workshop needs to build a reputation for good products, increase sales and thereby grow to support all its workers and train others. How would you report on this? Let us look at and discuss two examples. They have been adapted from a booklet by the ILO and Rehabilitation International.



EXAMPLE 1 Negative press coverage

“Crippled and Deaf-Dumb make jewellery in spite of handicaps”

About 30 crippled, deaf, dumb and blinded poor people have started a jewellery workshop on the east side of Harambee Plaza. They cannot walk or sit straight, most of them, and many used to be beggars.

Now, with all their problems and miseries between them, they will try to ignore their ugly fates and fashion something beautiful. With utmost patience and cheerfulness, they sit all day long putting together necklaces, bracelets and rings to appeal to passers by. To help them feel worthy, perhaps some charitable people would buy these trinkets.

What is wrong?

“Crippled” and “Deaf-dumb” are out of date, derogatory terms. “In spite of handicap” is patronising and reproducing a common stereotype portraying persons with disabilities as victims who are generally unable to work due to their disabilities. This approach focuses on inabilities rather than the many abilities that people have. The workshop is in this example described in pitiful terms, placing all the emphasis on physical conditions rather than on the workers skills and products. The necessary skills to produce jewellery do not include walking or sitting straight. The article has very few facts, it mainly reveals the writer’s prejudices and assumptions that life with a disability is a tragedy.

EXAMPLE 2

Positive press coverage

New jewellery shop opened by workers with disabilities

About 30 adults with various disabilities such as paraplegia, blindness, deafness and amputees, have started a jewellery workshop on the east side of Harambee Plaza. Following six months training in necessary skills, they produce 30-50 original necklaces, bracelets and rings a day in modern and traditional styles.

Mr Sharif Mousaka, the workshop manager who uses a wheelchair, says, "Some of us used to be beggars and we are now trained to support ourselves and help support other family members. Our jewellery is well-designed, beautifully made and competes with other products on the market". Mr Mousaka also says that any customer who brings a copy of this article will be given a discount on the first purchase.

What is right?

The headline puts emphasis on the new project. The disabilities is secondary. This article gives facts that readers would want to know. It does not dramatise the disabling conditions of the workers. The workers are portrayed as responsible adults who have obtained skills. The business is described in business terms, not in terms of a charity venture. The reporter has interviewed the manager, and quotes him as any other manager of a business would be quoted in a news story. The manager is given space to express his point of view in his own words.

"States should encourage the portrayal of persons with disabilities by the mass media in a positive way: organisations of persons with disabilities should be consulted on this matter."

- Rule 1: Awareness Raising, The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, The United Nations, 1994.

EXAMPLE 3

A review

Remix Dance Project is professional dance company in South Africa that brings together performers with physical disabilities and those without. Through their work they want to address the issue of accessibility to culture to ensure that people of all physical abilities can be full participants in cultural life. In 2002, Remix was awarded the prestigious *Arts Trust Award: Cultural Development Project of the Year* for its work.

Malcolm Black and Nicola Visser are both dancers in Remix Dance Project. After reading an appreciative review in a local newspaper Nicola felt obliged to write a letter to respond to the critic because of the way the review was written. Let us look first at how that review was written and then at Nicola's letter that was published in the newspaper.

The Review: «Remix Dance Company shines with fluid, graceful performances from talented quartet»

Establishing a professional dance group integrating physically disadvantaged people dancing alongside able-bodied ones - as Remix Dance Company is doing - may perhaps be belated, but it is a vitally important step towards empowering those with some infirmity to meaningfully participate in theatrical productions. And when a choreographer of Adam Benjamin's lateral thinking writes a work of the beauty and sensitivity of his *Second Time Broken* he unequivocally endorses the Remix Dance Company.

Nicola Visser and Mpotseng Shuping are not in any way handicapped. They are both attractive and technically efficient dancers. But Andile Vellem is deaf and Malcolm Black, in a wheelchair, has a rare disease affecting muscle control and speech. Yet Benjamin, building and capitalising on their strengths rather than dwelling on the duo's weaknesses (particularly Black's more obvious one) created an emotive state-of-the-art piece.

Making Katherine Glenday's delicate porcelain vessels the focus of his theme "only if you let go can you come back to me" Benjamin uses Neo Muyanga's earthy rhythmic sounds to weave graceful fluid port de bras and inventive upper body movements into artistic choreographic designs. This grace was well-reflected by the quartet, as well as Paul Abrams's aesthetically pleasing lighting plot and Hannah Leventhal's simple white flared pants and tops.

Ina Wichterich set the evening's opening number *I Can't Give You Anything But Love* to music by Billy Holiday and Muyanga.

Unfortunately, her awkward unrelated sequences emphasised Black and Vellem's frailties and didn't offset these by harnessing and showing Visser and Shuping's skills to advantage. Thus, it wasn't surprising that several patrons, not expecting that Benjamin's *Second Time Broken* would prove a gem, left at interval. Be sure not to do the same.

(Review by Sheila Chisholm, published in the Cape Times, South Africa, on the 6th of February 2006.)

The Letter: «New Views of Dance»

Companies such as Remix strive to renew our vision of who can and can't participate in today's culture and society. Sheila Chisholm's review (February 6), though appreciative of the dance company, fails to take note of the many changes that have taken place in disability politics.

It might be argued that a dance critic need not have specific knowledge of disability awareness, terminology or politics, but in reviewing a company like this, it drags the enterprise backwards to use terms such as "physically disadvantaged" and "empowering those with some infirmity" while noting how "attractive and technically efficient" the non-disabled members are. Remix is run and was founded by disabled and able-bodied people. Integrated companies have been performing internationally for well over 15 years. It is up to those reviewing such work to be aware of how to talk about disabled performers, the particular qualities they bring, how to place the work within the context of the arts as a whole and discuss it within the current thinking around disability.

As companies like Remix undo old ways of seeing, it is vital that critics, too, recognise their role in a changing society, lest we in dance are seen as inhabiting a fantasy world – something that Remix can never be accused of.

(Letter by Nicola Visser, published in the Cape Times on the 9th of February 2006.)

Why did she write the letter?

This is how Nicola explains why she wrote the letter to the newspaper:

- The problem with that review was vocabulary. If you are going to be writing in the public domain, if you are informing the public about what to see and how to see it, then, really, there has to be some research about that. Tackle it with honesty – say 'I feel uncomfortable, and I do not know what words to use'. Or research it and say that 'people with disabilities' is the term to use in South Africa, not 'handicapped' or 'infirm', which implies disease and something untouchable. Everybody must recognise their role in a changing society.

Her colleague Malcolm Black says:

- The field of integration between disabled and non-disabled is a completely new field. No one has got knowledge about it, because in this country disabled people have got their activities. Everybody has their activities. The two spheres have not met, they are completely separate. So when you tackle subjects like integration you should have the honesty to admit that no one really knows what is going on, because it has not happened much in this country.

- We have had another critic say that we insult the integrity of disabled people. It just means that she is shocked. She is saying that I am insulting disabled people on stage, but I have disability. I am not insulting myself.

What do you think?

Do you agree with their reasoning? How would you have reacted if you had received this letter as a response to one of your reviews or articles?

PUBLIC INFORMATION EXAMPLES

Public information on posters is another type of communication where persons with disabilities are seldom included as part of the general public, although they are as affected by these posters as anybody else. The first example below is typically not depicting anybody with a disability, although it targets 'anyone'. The second example is the only AIDS poster we have ever seen where a person with a disability is represented. Take a moment to look at the posters and think about the questions below.

Why are there no persons with disabilities in this picture?



How can this poster help?

