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Guidance Note on Disability and Development for EU Delegations and Services

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*This note provides guidance to EU delegations and services on how to address disability issues effectively within development cooperation. The note draws on material produced by the **European Disability Forum (EDF)** and the **International Disability and Development Consortium (IDDC)**.*

The European Year of People with Disabilities 2003

2003 is the European Year for People with Disabilities. It also marks the 10th anniversary of the UN Declaration of Disabled People and the UN Standard Rules on the Equalisation of Disabled People. The European Year provides an unprecedented opportunity for the EU institutions to give particular attention to the concerns of disabled persons in their work. EU delegations are encouraged to understand the European Year of People with Disabilities as an opportunity to start focusing particular attention on disability issues in their work and proactively to ensure the full and equal inclusion of persons with disabilities and their families in EU initiatives for developing countries in accordance with the key working principles developed in this guiding note. As part of its activities for the European Year, the Commission will also support the work of European NGOs working with NGOs from developing countries on disability issues.

Background

Disabled people make up approximately 10 per cent of any population (WHO) and 20 per cent of the world's poorest (World Bank). Disability is both a cause and effect of poverty, and 82 per cent of disabled people live below the poverty line in developing countries (UN). These figures can be higher in countries devastated by civil war or natural disaster. Disabled people, in all parts of the world, experience discrimination and

are widely excluded from the social, economic and political life of the community. This exclusion is the basic cause of high rates of poverty among disabled people in the poorest countries. Being amongst the most excluded has severe life or death implications for disabled people in developing countries.

Approaches to disability

The traditional way of addressing disability issues has been either through medical or charitable approaches, often based on the assumption that disability is an individual (bio-medical or functional) problem. Organisations for disabled people (rather than organisations made up of disabled people themselves) have provided segregated services, with little or no recognition of disabled people's rights to participate as equal citizens.

In the last few decades, disabled people's organisations around the world have promoted a human rights approach and an environmental approach to disability issues. These approaches are both based on a social model of disability. The focus is on disabled people's rights and on the need to change society to be inclusive of everybody. Within these models, it is the way that society is organised to exclude people with impairments that is considered disabling, not the individual impairment. Organisations of disabled people have been coming together increasingly to fight for their rights on this basis.

Governments have rarely considered the needs of disabled people when formulating their development cooperation agenda and have in most cases not made sufficient efforts to consult representatives of the disability community. Many donors, aid agencies and mainstream development cooperation NGOs do not consider the particular needs of disabled persons in their programmes or projects. Many do not have or practise policies of disability equality and thus exclude disabled persons from their activities. As a result, development cooperation largely excludes persons with disabilities. Gradually, however, the social and human rights approach to disability - as expressed in the World Action Programme (1982), the UN Standard Rules (1993), the International Classification of Functioning, Disability and Health (ICF, 2001) and in the approaches incorporated into EU policy - is being adopted by Governments and international institutions.

The European Union is committed to poverty reduction as expressed in the Millennium Development Goals. This goal cannot be met without considering the needs of disabled people; yet disabled people are still not sufficiently included in international development work funded by the EU. Realising key International Development Targets, such as universal primary education, would be impossible without including disabled people. If the interests of disabled people are not recognised then the key goal of poverty reduction in developing countries will not be achieved. Nor will the human rights of people with disabilities or their participation in society be promoted. If sustainable poverty reduction is to be achieved, disability needs to be addressed by sensitising people active in development work funded by the EU to these issues.

Key issues

Exclusion, marginalisation and vulnerability

Disabled people experience discrimination from birth, or from the moment of becoming disabled, onwards. The birth of a disabled child is often considered a tragedy. A disabled child needs more attention and may not be considered to have the potential to support him or herself, let alone the older generation, in the future. In communities that are already living in chronic poverty this is very significant. Disabled children may be protected and cared for, but are often excluded from the day-to-day activities of the family and the community. Their voice goes unheard.

Disability is often perceived in a very negative way due to cultural factors, ignorance, superstitions and fear. In some places, disability is seen as a curse or punishment from God; disabled people are perceived as being sub-human and unfit to participate in society's mainstream activities. Many families of children with disabilities both fear for and are ashamed of them. They tend to hide disabled children and do not offer them any opportunities for development. Where disabled people are not visible in society advocacy for disability rights is made all the more difficult.

Many disabled persons develop a dependency syndrome, inferiority complex, a sense of resignation and feelings of isolation and exclusion from the society in which they are born and live. It is clear, however, that many of the problems encountered by people with disabilities are not solely caused by perceptions or by culture. Cultures and perceptions vis-à-vis disability differ from country to country, and there are also differences in this regard between rural and urban environments.

Basic resources - food, health care, education

Where there are limited resources it may be seen as economically irresponsible to give an equal share of resources to a disabled child who is considered unlikely to be able to provide for the family in future. In situations of extreme poverty, this may be a desperate but rational decision. Disabled people are often given the lowest priority for any limited resources, including food, clean water and land. This leads to poor health. This situation is particularly stark in emergency situations. Many relief and refugee organisations do not adequately consider the needs of disabled people. However, recent experiences, such as the work done by Handicap International in ex-Yugoslavia (largely funded by the European Union), show that disability issues can be addressed successfully, even in difficult circumstances.

Health care

All disabled people have the same needs for basic health services as anyone else. This is often denied. Health centres may be physically inaccessible and/or far away (particularly in rural areas) and health workers may discriminate against them. Disabled women frequently complain of doctors denying them access to reproductive health services. Information on health care is often not provided in accessible formats and disabled persons are not targeted for health education. Some disabled people have specific medical needs associated with their impairments. In particular, in post-conflict zones (e.g. in Bosnia, Kosovo, Rwanda or Sierra Leone), there may also be a need for access to psychological expertise. Meeting such needs is a prerequisite for achieving full participation.

Education

Universal primary education is unobtainable without the inclusion of disabled children. 98 per cent of disabled children receive no formal education (UNICEF). Even if the school is physically accessible, many disabled children remain excluded. Parents may fear that the child will not cope or that disclosure of a disabled child will stigmatise the whole family and affect the marriage prospects of siblings. 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 equally. Disabled children often have fewer demands placed on them and therefore may learn less than non-disabled siblings even in an informal setting. Right from the start they are excluded from many of the day-to-day interactions that non-disabled people take for granted.

However, lack of access to education should not be seen only as a question of overcoming cultural barriers. Attitudes of the teachers, physical accessibility of schools and transport and access to orthopaedic material and equipment are issues that also need to be addressed. In order to be effective, inclusive education requires investment in building a barrier-free environment. This involves appropriate teacher training, curriculum development and providing the necessary support for disabled children. There is also a need for developing special education programmes in which children with disabilities can get more and appropriate attention.

HIV and AIDS

Disabled people are particularly affected by and vulnerable to HIV and AIDS. Many disabled people are also indirectly affected by HIV and AIDS. They are often dependent on their families and due to HIV/AIDS they risk losing the family who is assisting them. They have inadequate access to information, health care and treatment. Information is rarely available in appropriate formats for disabled persons or adjusted to existing needs. As only very few of the world's disabled people obtain any form of education, illiteracy is also widespread. There is a lack of information provided in sign language for deaf and hearing-impaired people, in Braille for visually impaired people and in any kind of accessible form for disabled people with learning or intellectual disabilities.

The sexuality of disabled persons in general, and women with disabilities in particular, is something unknown and often stigmatised and is therefore infrequently discussed. Disabled persons are simply presumed not to have sexual contacts, which is yet another reason why information about HIV and AIDS does not reach these groups.

Employment

Later in life, disabled people have restricted employment opportunities, due to discrimination, lack of education, experience and confidence. In fact, employment opportunities for disabled people in developing countries are often almost non-existent. Many disabled persons have to beg for a living whereas, in actual fact, employment is the only way out of life long exclusion. If, during childhood, disabled children are not included in the community, then as they grow up, their non-disabled peers may not be aware of their existence, let alone their value and rights as equal citizens.

Exploitation

Disabled persons in the workplace are paid meagre salaries compared to the able-bodied, and those with qualifications often lack opportunities to use them due to work place discrimination. Exploitation is worse for people with intellectual disabilities and those with speech and hearing impairments. In developing countries they may gain more from begging than as workers (which sometimes leads to new forms of exploitation).

Poverty

Exclusion leads disabled people to fall further into chronic poverty with little opportunity of breaking out of the cycle. When the main family breadwinner becomes disabled, the whole household risks sliding more deeply into poverty. Removing barriers and enabling disabled people to contribute could help reduce poverty in the whole community. Conversely, without their inclusion, sustainable poverty reduction for the whole community will be unachievable.

Access barriers

In addition to social and attitudinal barriers disabled people also face architectural and environmental barriers that limit access to community services and facilities and hinder equal participation. Most roads, houses and public utilities – including public transport - do not cater for special mobility needs. Little or no attempt is made to legislate to require accessibility provisions in public services. Persons with sensory disabilities are completely cut off from the information world when public services fail to provide information in accessible formats, such as Braille, sign language and easy-to-read texts.

Political processes

Disabled people are frequently excluded from decision-making processes, including the fundamental right to participate in elections. This is most often due to barriers to access, such as lack of access to information and lack of access to voting booths. In order for disabled people and their families to be heard by decision-makers it is important for organisations of disabled people themselves and their families to be consulted on issues and decisions that affect them.

Specific concerns of disabled women

Disabled women and girls face double exploitation and discrimination. They are often excluded from education, health services, family life and employment and experience high rates of sexual abuse with the high risk of contracting HIV/AIDS. They often have low self-esteem and confidence resulting from a life of discrimination and exclusion.

The way forward - principles for EU delegations and services

1. Understand the scale and impact of disability in the country setting and recognise the diversity of the disabled population

Disabled persons do not form a homogeneous group of people. Only policies that respect this diversity will work. In particular, people with complex dependency needs and intellectual disabilities, as well as their families, require particular action by societies as they are often the most forgotten among disabled people. Also, disabled women and disabled people from minority groups are often faced with double and even multiple discrimination, resulting from the interaction of the discrimination caused by their disability and the discrimination resulting from their gender, age, tribe or caste.

2. Advocate and support the human rights model of disability rather than the charitable or medical approach

Disabled people want equal rights, not charity. EU policy on development cooperation, as well as the supporting actions of the EU country delegations, must reflect this approach. Disabled people are entitled to the same human rights as all other citizens. The first article of the Universal Declaration on Human Rights states that “All human beings are free and equal in dignity and rights”. In order to meet this standard, all people should celebrate the diversity within their communities and seek to ensure that disabled people can have the full range of human rights – civil, political, social, economic and cultural – as acknowledged by the different international Conventions, the EU and EC Treaties and in the different national constitutions.

The UN Standard Rules on the Equalisation of Persons with Disabilities¹ is the principal document, which forms the basis for the rights-based approach to disability and which the EU should be following in its work on development cooperation.

3. Pursue a twin-track approach

There is a need both to mainstream disability issues across all relevant programmes and projects and to have specific projects for disabled people. This means that disability concerns should be recognised in the main EU funding programmes, such as transport and infrastructure, but also addressed through specific disability projects (including capacity building) for disabled people.

Ensuring access for disabled people should be integral to all activities supported by EU delegations

There is a clear link between the issue of disability and the basic principles of the European Community’s Development Policy: promotion of human rights, poverty eradication and action to combat inequality. Therefore, it is essential that the EU in all its development cooperation initiatives recognises the needs and rights of people with

¹ UN Resolution 48/96, 20 December 1993: gopher://gopher.un.org/00/sec/dpcsd/dspd/disabled/ar48-96.en

disabilities. Disability should be adequately reflected within country strategy processes and EU documentation.

Ensure the inclusion of disabled people – “Nothing about us without us”

Ensure that disabled people participate in the development of any programme designed to benefit them. A starting point for ensuring that disabled people are fully included is to ask them what their needs are. Nobody knows as much about disability and the processes of exclusion as disabled people themselves. It is essential to consult regularly with representative disabled people’s organisations. One approach which can contribute to the empowerment of disabled people is the so called Community-Based Rehabilitation (CBR). This strategy should be implemented through the combined forces of people with disabilities, their families and communities, and the appropriate health, education, vocational and social services.

4. Assess, as part of the mid-term review, to what extent the country programme is inclusive of persons with disabilities

EU delegations should examine, as part of the mid-term review, and together with various partners in the country, the extent to which the country programmes are responsive to the needs of persons with disabilities. This analysis should take into account the EU-ACP Joint Parliamentary Resolutions on Persons with Disabilities.²

5. Ensure EU funded projects are truly inclusive of disabled persons and their families

EU programmes need to involve and include organisations of disabled people themselves and families, not just governments and non-disabled persons speaking on behalf of the disabled community. In countries where the necessary infrastructure is missing, representative disability organisations are often the only ones who actually achieve anything through self-help. Disability should also be included in the terms of reference for social impact assessments. Together with partners, delegations should analyse and monitor to what extent EU funded projects in the host country include disabled persons. Mechanisms should also be put in place to ensure effective participation of representative disabled people’s organisations in all initiatives. When addressing disability it is important to take the family situation into account. Experience from traditional societies shows that support by and through the family is often a very positive factor when addressing the needs of people with disabilities.

² Resolution on the rights of the disabled people and older people in ACP countries ACP-EU 3313/01/final. Resolution on health issues, young people, the elderly and people living with disabilities ACP-EU 3398/02/final.

6. Recognise women and children with disabilities in programmes

It is important to design programmes and projects in a way that secures gender equality and for both men and women to have equal influence on the design, decision-making and implementation. Furthermore, as women and children with disabilities are often severely marginalised, specific initiatives are required to reduce exclusion and discrimination by:

- Education projects aimed specifically towards women and children with disabilities
- Strengthening of disabled women's networks and networks of parents of children with disabilities
- Specific programmes for children with disabilities in post-conflict societies (including through reinsertion of child soldiers)

7. Include disabled people in the workforce

An inclusive organisation working on poverty issues should employ a reasonable proportion of disabled people among their staff. However, working with specific quotas has a mixed record and does not necessarily improve the overall situation. A more fruitful approach would be to ensure that disabled people are fully included in EU funded training and employment programmes. EU delegations should also be open to employing disabled persons in their offices. Useful advice can be found in the ILO Code of practice on managing disability in the workplace.³

8. Ensure that the EU's own services are accessible for disabled persons

EU delegations' offices should continue to ensure that they are physically accessible. Information should be produced in a variety of formats to be accessible to disabled people. EU delegations should undergo disability equality training. Staff should be made aware of the need to include disabled people in planning, implementing and evaluating work.

9. Facilitate and support capacity building of representative disability organisations

EU delegations should make deliberate efforts to facilitate the process of establishing or strengthening disabled people's organisations. This could be supported through funding of capacity building for organisations of disabled people and their families in order that they can be empowered and, thereby, have increased influence in decision-making. It is also important to support organisations responding to the needs of people with disabilities, e.g. parents' organisations, professional organisations for social workers or special teachers and wider organisations that include people with disabilities, e.g. women's or youth organisations.

³ ILO, Code of practice on managing disability in the workplace, Geneva, October 2002: <http://www.ilo.org/public/english/standards/relm/gb/docs/gb282/pdf/tmemdw-2.pdf>

10. Facilitate communication between disability organisations and Government and other stakeholders

EU delegations should play a leading role in sensitising Government and other relevant agencies and stakeholders (such as Embassies and donor agencies) operating in the respective countries to promote the inclusion of disabled people in their work programmes. They should also facilitate communication (for example by organising round table meetings or by chairing meetings) between these agencies and stakeholders and representative disability organisations.

Further information can be found at:

USAID Disability Policy Paper (USAID, September 1997)
<http://www.usaid.gov/about/disability/DISABPOL.FIN.html>

“The Inclusion of Disability in Norwegian Development Co-operation” (NORAD, January 2000)
<http://www.norad.no/norsk/files/InklusionOfDisability.doc>

“Disability, Poverty and Development” (DFID - UK Department for International Development, February 2000)
<http://62.189.42.51/DFIDstage/Pubs/files/disability.pdf>

“Access for All” (Save the Children, November 2000)
<http://www.savethechildren.org.uk/scuk/jsp/resources/details.jsp?id=657&group=resources§ion=policy&subsection=details>

“Schools for All: including disabled children in education” (Save the Children, 2002)
http://www.eenet.org.uk/bibliog/scuk/schools_for_all.shtml

“Inclusion of the disability dimension in Nordic development cooperation” (Report of the Copenhagen conference on development and disability, November 2000)
<http://odin.dep.no/odinarkiv/norsk/dep/ud/2000/taler/032091-990449/index-dok000-b-f-a.html>

RESOLUTION on the rights of the disabled people and older people in ACP countries ACP-EU 3313/01/fin
http://europa.eu.int/eur-lex/pri/en/oj/dat/2002/c_078/c_07820020402en00220083.pdf

RESOLUTION on health issues, young people, the elderly and people living with disabilities ACP-EU 3398/02/fin
http://europa.eu.int/eur-lex/pri/en/oj/dat/2002/c_231/c_23120020927en00190066.pdf

Key disability umbrella organisations and networks working in the field of development cooperation

International Disability Alliance (IDA) um@inclusion-international.org
The International Disability and Development Consortium (IDDC) www.iddc.org.uk
European Disability Forum (EDF) www.edf-feph.org

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