Disability as a human rights issue
Background paper to conducting a dialogue
Disability as a human rights issue
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There is a broad consensus that disability is a human rights issue. This is reflected in the international human rights treaties ratified and national legislation for the equal rights of persons with disabilities adopted in many countries around the world. In the rhetoric and on a policy level, few disagree. In terms of actual implementation, however, little is done to protect the rights of persons with disabilities. To achieve results, a policy dialogue must be brave and move beyond the policy consensus and focus the discussion on the concrete actions needed to move towards a more inclusive society.

Shuaib Chalklen, UN Special Rapporteur on Disability, 23 March, 2010

In 2009, non-discrimination with special focus on the rights of persons with disabilities (PwD) was selected as one of Sida’s high profile issues within the area of Democracy, Human Rights and Gender Equality. A work plan on how to address this challenge was adopted and launched in December 2009. The development of this dialogue brief is part of the implementation of the work plan. It aims to be a useful tool to assist Sida staff to conduct dialogue on the inclusion of PwD in development cooperation at global, regional and country levels.
Disability as a human rights issue

The purpose of this paper is to provide information that can be used by Sida staff in dialogue with partner governments, co-donors and multilaterals to promote the rights of persons with disabilities within the development agenda in general and in budget support and sector programs in particular. It contains basic facts, key issues and suggested dialogue questions, which provide a “smorgasbord” of dialogue entry points depending on the given context and circumstances. To reach concrete results, it is important to focus on a few issues in a consistent and coherent manner.

EXECUTIVE SUMMARY

Disability is a multi-dimensional concept and persons with disabilities are denied their rights in one way or the other, in a number of aspects of life. All issues, however, cannot be tackled at once and therefore this paper has identified the following challenges and key dialogue issues to be critical and relevant.

Main dialogue challenges

• To facilitate the dialogue and ensure that Sida support indeed contributes to increased protection of human rights and reduced poverty among the most marginalised, Sida staff can make use of the fact that several developing countries have signed and/or ratified the Convention on the Rights of Persons with Disabilities (CRPD) and also that a number of multilaterals and bilateral donors have adopted disability policies which could form a basis for joint dialogue platforms with governments.

• Because of invisibility and powerlessness of persons with disabilities, partner governments tend to see disability as a minor issue affecting only a few. To challenge this, donors can refer to research showing that in fact 25% of populations are affected and that in some countries as much as 40% of the poor, are persons with disabilities including their families. The millennium development goals cannot be fully reached if issues of persons with disabilities are not taken on board.

• It is generally acknowledged that there is a need for a twin track approach to address inequalities and discrimination of persons with disabilities. Inclusion of persons with disabilities in ordinary development programs is not only about tackling accessibility barriers, negative attitudes and knowledge gaps. It is also about building the capacity of persons with disabilities and their organisations to access programs and compensating for limitations. Persons with disabilities and their organisations stipulate a weak lobby group due to limited educational opportunities, low self-esteem, weak organisational structures and competing agendas within the disability movement. Meaningful participation of persons
with disabilities in programming requires specific attention to strengthen the voices of persons with disabilities and assist them in preparing and accessing the development dialogue forum. Support needs to be tailored to the context in each country. Thus, a twin-track approach which includes both specific initiatives that targets and empowers persons with disabilities and general/mainstream measures addressing the discrimination of persons with disabilities is the best way forward in order to achieve maximum results.

- It is assumed that the costs related to inclusion of persons with disabilities are too high for a developing country and as such a luxury that can be dealt with later on. To challenge this conception, there is research showing that investing in inclusion, accessibility, rehabilitation and education of persons with disabilities is economically beneficial to all. Studies show that the cost to society in the form of lost GDP due to disability outweighs the relatively low investment costs needed to create inclusive environments and programmes.¹

**Priority Issues**

The following priority areas could be observed:

- Promote meaningful participation of persons with disabilities in planning processes, such as Poverty Reduction Strategies – PRS, sector programs, human rights initiatives and civil society consultations.

- Ensure that Disability Persons’ Organisations (DPOs) are properly informed and prepared for participation in these processes.

- Request progress reports related to men, women and children with disabilities in PRS, sector programs and other development initiatives, where specific indicators already exist for marginalized groups or persons with disabilities.

- Promote proper baseline studies on the situation of persons with disabilities to capture data that can be used when developing indicators.

- Use the new Convention on the Rights of Persons with Disabilities (CRPD) as a dialogue tool and promote the establishment of national monitoring mechanisms.

Disability is an evolving concept and results from the interaction between persons with long-term physical, mental, intellectual or sensory impairments and the attitudinal and environmental barriers that hinder their participation in society on an equal basis with others, as defined by the UN Convention on the Rights of Persons with Disabilities (CRPD).

Different expressions are used when referring to persons with disabilities. This paper uses the term “persons with disabilities” (PwD) consistent with the language used by the UN.

GENERAL SITUATION OF PWD IN DEVELOPING COUNTRIES

There are approximately 650 million persons with disabilities in the world, or 10 per cent of the global population, making them the world’s largest minority. It is estimated that about 80% of persons with disabilities live below the poverty line and comprise one of the single largest groups of excluded and chronically poor people in the world. In both developed and developing countries, evidence show that PwD are disproportionately represented among the world’s poor. It is estimated that of those who live on less than one dollar a day and who lack access to basic necessities such as food, clean water, clothing and shelter, one in five is a person with some kind of disability. National census and household surveys in developing countries rarely provide accurate data on disability. Due to underreporting and inadequate data gathering, many developing countries report very low rates of disability, often 1–2%, while it is predicted that disability prevalence is between 10–20% and even higher in countries where major conflicts or natural disasters have occurred. According to UN estimates, at least 25% of any population in developing countries are directly or indirectly affected by the presence of a disability in the family. Less than 2% of PwD have access to rehabilitation and less than 5% have access to education. The global literacy rate for PwD is as low as 3% and 1% for women with disabilities. Unemployment among PwD of working age is believed to be 80–90% in developing countries.

1. www.un.org/disabilities/default.asp?id=33
WOMEN WITH DISABILITIES

In most countries, the prevalence of disability is reported to be higher among women than among men\textsuperscript{11}. Women with disabilities are recognized to be multiply disadvantaged, experiencing severe discrimination and exclusion based on their gender and their disability. Women with disabilities are often excluded from education, health services, family life and employment and experience high rates of physical, mental and sexual abuse, the latter substantially increasing their risk of contracting HIV/AIDS. Women with disabilities, particularly those in rural areas, often lead an existence of subservience, with little or no control over their own lives\textsuperscript{12}. At the same time as women with disabilities are more likely to be victims of violence and rape, they are also much less likely, in comparison to non-disabled women, to receive police assistance and legal protection\textsuperscript{13}. A small survey in Orissa, India (2004), found that virtually all of the women with disabilities were beaten at home, 25% of women with intellectual disabilities had been raped and 6% of women with disabilities had been forcibly sterilized\textsuperscript{14}. Women with disabilities around the world report that in spite of their extreme need, they are often denied meaningful participation in community projects, international development programs and lack access to initiatives, even those targeting women\textsuperscript{15}. For instance, microcredit programs targeting women sometimes use selection criteria, lending procedures and training facilities that discriminate against women with disabilities, either directly or indirectly through inaccessibility\textsuperscript{16}.

CHILDREN WITH DISABILITIES

One third of persons with disabilities are children. The mortality rate for children with disabilities in developing countries may be as high as 80% in countries where the under-five mortality rate in general is below 20%\textsuperscript{17}. Research indicates that violence against children with disabilities occurs at annual rates at least 1.7 times greater than for their peers without disabilities\textsuperscript{18}. According to UNICEF, 30% of street youths have some kind of disability\textsuperscript{19} and according to UNESCO 90% of children with disabilities in developing countries do not attend school\textsuperscript{20}.

\textsuperscript{12} http:/ /www.un.org/disabilities/convention/facts.shtml
\textsuperscript{13} http:/ /www.un.org/disabilities/convention/facts.shtml
\textsuperscript{14} http:/ /www.miusa.org/publications/books/mti/chapter3
\textsuperscript{15} http:/ /www.un.org/disabilities/convention/facts.shtml
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\textsuperscript{17} http:/ /www.un.org/disabilities/convention/facts.shtml
\textsuperscript{18} http:/ /www.un.org/disabilities/convention/facts.shtml
\textsuperscript{19} http:/ /www.unicef.org/explore_3893.html
WHAT IS BEING DONE

The Convention on the Rights of Persons with Disabilities (CRPD) has provided new impetus for disability-inclusive, rights-based development around the globe. Many governments and several multilateral development agencies are either in the process of drafting new disability policies or strategies or are reviewing their existing approaches with the intent of modifying or amending them\(^{21}\). Recent research shows that countries in all parts of the world have adopted equal opportunity legislation in the context of disability\(^ {22}\). More than 40 states around the world have now adopted anti-discrimination laws for PwD\(^ {23}\).

On the implementation side, however, a gap exists between legislation and policymaking and concrete actions. A lot still needs to be done to protect the rights of persons with disabilities in developing countries.


\(^{23}\) http://www.un.org/disabilities/default.asp?id=235
Sida and many other actors in international development cooperation, including UN and European Union development agencies as well as many NGO’s, have increasingly adopted a human rights-based approach to development. This approach is inclusive and calls for the participation of all concerned groups, particularly socially excluded and discriminated groups in the development process. The human rights-based approach is based on the four principles of: participation, non-discrimination, transparency and accountability.

PARTICIPATION

“Nothing about us without us” is a slogan adopted by Disabled People’s Organisations worldwide. It means that only with meaningful participation of Persons with disabilities themselves in the development process, will we be able to see results in the protection of rights of PwD. Sometimes, it may cost a bit extra to invite PwD into the processes (preparations, accessibility, assistants and interpreters), but this is important in order to achieve sustainable results.

The concept of empowerment can accompany meaningful participation. It is important to take into account that PwD often face difficulties in meaningful participation because of stigma, physical, communicative or intellectual barriers, and low level of literacy and self-esteem. Even within their own families, persons with disabilities are often isolated and neglected. Empowerment of PwD is therefore a long process that starts within the family and community and requires both attitudinal change, removal of barriers and access to basic services. Equality and empowerment of persons with disabilities is an important element to a human rights-based approach and should aim to empower PwDs, so that they can make informed choices, advocate for themselves, and exercise control over their lives and be both agents and beneficiaries in the development processes.

NON-DISCRIMINATION

The disability rights debate on discrimination is not so much about the enjoyment of specific rights as it is about ensuring all human rights without discrimination. However, broad human rights frameworks and international, regional and national legal mechanisms that do not explicitly mention discrimination on the grounds of disability are usually not adequate to ensure those rights. Therefore, additional laws that specifically address the discrimination faced by PwDs have been adopted in many countries. However, deeply ingrained stigma, and the common misconception that PwDs cannot make contributions to family and society makes it difficult to enforce these laws.

http://www.undp.org/governance/focus_human_rights.shtml
OPENNESS AND TRANSPARENCY

It is important to acknowledge that persons with disabilities do not always access information in the same way as other citizens, due to social exclusion and disabilities such as limitations in seeing, hearing, or understanding. In addition, the low levels of education make it difficult for many to access standard written information. For some, the right to have sign language as the first means of communication in schools is crucial to learning. Training and certification of professional sign language interpreters is therefore an important part of any “right to information” program. Other examples of alternative ways to provide information would be Braille or audio-sound for persons with visual impairments.

ACCOUNTABILITY

In the area of disability, governments are often not held to account for the commitments made to PwDs. Political commitments sometime need to be accompanied by earmarked budget allocations, indicators of progress or monitoring mechanisms. Persons with disability often do not have a strong voice, advocacy skills or facts to support their case. Access to justice for PwDs is limited. Legal assistance programs that take on cases of rights violations for PwD are rare. There is a strong need for a system of accountability based on public and transparent information that enables communities and DPOs to monitor the performance of the local government and to react appropriately to their performance.

POVERTY AND DISABILITY

The inter-linkages between disability and poverty varies within and between cultures and contexts, but the relationship is generally acknowledged to be strong. Poverty and disability is a two-way relationship – poor people are more likely to have a disability because of the conditions in which they live with limited access to health care, adequate nutrition, safe working environments and proper sanitation. Disability, on the other hand, is likely to make people poorer because of limited opportunities, lack of access to education, health care, transportation, communication, housing, and employment as well as discrimination and abuse. It is generally held that the link between poverty and disability is due to discrimination, social exclusion and denial of rights together with a lack of access to basic services. Therefore, development is about removing barriers and reducing discrimination to bring excluded into the mainstream of society so that they can attend school, go to work, raise a family, access health and rehabilitation, be members of political parties, participate in religious institutions, get on buses, answer the phone, and access the Internet etc.– like other citizens.

Mitigating the negative consequences of the two-way relationship between disability and poverty is increasingly recognized as a necessary component of any successful poverty alleviation scheme. Ensuring equality of rights and access for these persons is likely to have a positive impact on the social and economic situation in countries around the world.
DISABILITY AND INTERNATIONAL HUMAN RIGHTS INSTRUMENTS AND INITIATIVES

PwDs are entitled to the same human rights and freedoms as everybody else. The problem of invisibility of PwDs in the mainstream human rights system, however, poses some challenges in the implementation of human rights of PwDs. In response to this problem, international human rights instruments which explicitly mention PwD have been developed over the years. The three specialized documents which have particular significance to the rights of PwD are: The Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol. The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (the Standard Rules) and the World Programme of Action concerning Disabled Persons (WPA).

The Convention on the Rights of Persons with Disabilities (CRPD)
The process of elaborating the CRPD, initiated in 2001, provided an opportunity to manifest a paradigm shift in the area of disability. The long advocated human rights approach to disability, mainly from and by PwDs themselves, is clearly manifested in this convention. The CRPD tackles the rights of PwD from an anti-discrimination perspective. It builds upon, and works in synergy with, other international human rights instruments with an objective to promote, protect and ensure PwD’s full and equal enjoyment of all human rights. The CRPD is a human rights instrument with an explicit social development dimension and is the only international human rights instrument to contain an article on international cooperation (article 32) providing a comprehensive normative framework for mainstreaming disability in the development agenda. A “Committee on the Rights of Persons with Disabilities” of independent experts has been established and is tasked to monitor the implementation of the Convention by the States Parties. In addition, an Inter-Agency Support Group for the Convention has been established. The Inter-Agency Support Group, in turn, has established a UN Development Group (UNDG) task team involving a number of UN agencies to support United Nations country teams and relevant stakeholders to mainstream disability in development cooperation.

Optional Protocol
The Optional Protocol covers only a certain aspect of the CRPD and gives the monitoring body the power to hear individual complaints of violations of rights as articulated in the Convention. Optional Protocols must be separately signed and ratified by each State Party. The Optional Protocol creates additional functions for the Committee on the Rights of Persons with Disabilities by considering complaints from individuals or group of individuals claiming to be victims of violations of their rights. The committee members may conduct an inquiry on a State Party following such complaints.

25 To find out current status on the ratification process visit: http://www.un.org/disabilities/index.asp
INTERNATIONAL LEVEL ACTORS

Most of the major international development actors, including UN agencies, the World Bank, the European Commission (EC) and some international civil society actors acknowledge disability in one way or the other and include disability, to different degrees, in their policy documents. PwD rights are gaining momentum in policymaking also at national and local levels.

Some of the UN agencies that have specific focus on PwD rights:
- UNDP coordinates the MDG work and specifically targets PwD in interventions in the areas of democratic governance, poverty reduction, crisis prevention and recovery, energy and environment, information and communications technology.
- UNICEF promotes the rights of children with disabilities.
- WHO supports member states in the development of policies, CBR-strategies, services and implementation of the UN Standard Rules.
- ILO promotes accessibility in labour markets and trains its staff on disability-related matters.
- UNESCO focuses on the promotion of inclusive education for all children with disabilities.

Other global players in the area of disability:

World Bank

World Bank focuses on inclusive development and human capital development as necessary components to achieve the MDG’s. It builds partnerships with other development agencies to increase the inclusion of disability issues in development and generates knowledge and documents good practices with regards to inclusion of a disability dimension.

Global Partnership for Disability and Development

The World Bank founded the Global Partnership for Disability and Development (GPDD) in order to increase collaboration among development agencies, international organizations and civil society organizations, particularly DPO’s, to reduce the poverty and exclusion of PwD and their families living in developing countries.

EU

EU is a key actor in the area of disability and development. The European Parliament adopted a resolution on Disability and Development in 2006 and ratified the CRPD in 2009. EU is committed to ensure that disability is included in its development policies and programmes

Civil society
The International Disability Alliance (IDA) and the CRPD Forum are networks of global and regional DPOs and actors promoting the implementation of the CRPD. International organisations of persons with specific disabilities include Disabled People International, The World Blind Union, International Federation of Hard of Hearing, World Federation of the Deaf, Inclusion International, Rehabilitation International, World Federation of the Deaf and the World Network of Users and Survivors of Psychiatry. The International Disability and Development Consortium (IDDC) is a global consortium of 23 disability and development NGOs supporting disability and development work in more than 100 countries globally. Shia – Swedish Organisations of Persons with disabilities International Aid Association is one of Sida’s frame-organisations, focusing exclusively on disability and development. Shia was formed in 1981 and consists of 30 Swedish organisations of PwD which are actively involved in international development cooperation.

NATIONAL LEVEL ACTORS

Authorities
At national level, a wide range of ministries and government agencies are responsible for specific PwD rights and disability programs. In many countries the leading ministry is often the Ministry of Health or the Ministry of Social Affairs. The Social Welfare Ministry is usually responsible for welfare programs for PwD, often carried out in collaboration with NGOs and DPOs. The Ministry of Health usually has responsibilities for prevention and early identification of disability as well as the provision of medical services needed for rehabilitation. The Ministry of Social Affairs focuses on rehabilitation and social services for PwD. The Education Ministry is responsible for providing education for children with disabilities. The Ministries of Women’s Affairs, – Labour, – Transport, and – Public Administration also have responsibilities towards persons with disabilities. The key roles of government agencies is to set standards for rights and entitlements and monitor implementation, provide resources and ensure that public services are accessible to PwDs. Most governments have a National Disability Council (NDC) or the equivalent as the focal point for disability issues. The NDC is usually composed of representatives from national government agencies, NGOs, and DPOs. Its main function is usually to develop a national plan of action on disability, coordinate and promote effective cross sector/cross ministerial action on disability in the country and develop capacities amongst all stakeholders.
African Decade Steering Committees
African Decade Steering committees exist in some African countries as part of the African Regional Decade Initiative. The committees engage in advocacy, development of national plan of actions and monitoring and are comprised of representatives from DPOs, ministries and other stakeholders in the area of disability26.

Civil society
Disabled people’s organisations focus on the promotion of PwD rights, representing the interests of PwD in advocacy, monitoring of government performance and service provision to their members. In the majority of cases, these organisations have to be mainly composed and led by persons with disabilities. In many countries, there are umbrella DPOs and a few well-established, national and community-based DPOs that actively engage in policy dialogue with communities, the national government, donors, and multilateral agencies, banks, other NGOs and implementing agencies. Most DPOs, however, have weak structures and lack sufficient capacities to be a strong voice. Disability service providers are agencies such as development NGOs, faith-based organisations, DPO’s or private companies which provides specialised services (fitting of prosthetics etc) or inclusive services (livelihood etc) for PwD aiming at reducing the impact of impairments through support of health care, rehab, livelihood services, advocacy, research etc.

Local level
The majority of persons with disability live in rural areas and roles and responsibilities of actors at local and municipal level is therefore crucial to the implementation of rights of PwD. The general decentralisation processes, in many developing countries, over the last two decades further points to the need for creating permanent spaces for dialogue between local authorities and local DPOs. Local authorities need to be informed and responsive to the rights of PwD in the community when allocating funds and taking measures. DPOs and PwDs at local level need to be informed and involved in the process of policy making, planning and implementation. This requires substantial efforts as ignorance among local officers is rife and capacity of local DPOs is generally low.

KEY BILATERAL DONORS IN THE AREA OF DISABILITY
When working in alliances with other donors it is important to identify those who are like-minded and to formulate a joint dialogue strategy. Below is a list of some of the donors that can be useful allies in the area of disability.

DFID – Great Britain
For many years DFID has been a leading proponent among donors for integrating disability in development practice, and UK legislation now mandates DFID to promote disability equality. Disability will also be a key issue in the social exclusion analysis which informs the CAP

26 For more information visit: http://www.africandecade.org
process. In October 2007 DFID published a How to note, and a policy on disability from year 2000 and between 2003–2005 DFID funded important research on disability and development (Disability knowledge and research).

GTZ – Germany
GTZ is an important actor in the field of inclusion of PwD in development cooperation. In 2006 GTZ drafted a national policy paper, in which the German ministries and authorities agreed to a common approach on this issue. The human rights of PwD and “inclusive development” are of central importance to GTZ. It is seen as a precondition for addressing issues of poverty reduction, human rights and equality. In 2008 GTZ funded a study on “Disability and Infrastructure” which provides a compilation of international best practice examples and practical recommendations for action to set up barrier-free, low-cost structures that are appropriate for developing countries and PWD. GTZ has also worked with inclusion of PwD in HIV/AIDS programs, especially in Tanzania.

AusAID – Australia
On 25 November 2008, Australia launched Development for All: Towards a disability-inclusive Australian aid program 2009–2014, publicly committing the Australian Government to ensuring that PwDs are comprehensively included and supported in improving their quality of life through all aspects of the aid program. An AusAID’s Disability-Inclusive Development Reference Group was established to provide strategic guidance to the Australian aid program on implementation of its disability-inclusive development strategy. The strategy seeks to improve the quality of life of PwD through a range of programs and funding mechanisms — including targeted initiatives to meet the specific needs of PwD, building the leadership skills of PwD and their organisations, and ensuring major programs in sectors such as education and infrastructure meet the needs and priorities of PwD. The strategy will also focus on reducing preventable impairments through support for avoidable blindness and road safety. It will seek to improve our understanding of disability and its links to poverty through strengthened research and data and build AusAID’s leadership and advocacy role in promoting disability as a development priority.

Austrian Foreign Ministry – Austria
Austrian Foreign Ministry was one of the first countries to adopt a strong disability focus in its programmes and guidelines. The Austrian development cooperation, State Secretary reaffirmed in 2008 that Austria will continue to undertake every possible effort to realise an integrated society. With regards to disability and development, Austria has committed itself to take a leading position both at the European and the international level. It should be noted that few of the Austrian policy documents are available in English.

Italian Development Cooperation, Italy
Italy also highlights the rights of PwD in its development cooperation policies. One out of the five recently published guidelines is on PwD. So far the documents are only in Italian.
The other Nordic countries

Traditionally the Nordic countries have been in the forefront in terms of promotion of the rights of persons with disabilities in development cooperation. In year 2000, the Nordic Foreign Ministers made a joint commitment to continue focusing on the rights of PwD in their international work and to continue cooperating and sharing experience on these matters. All Nordic countries still embrace values of human rights and prioritise poverty reduction, and they contribute to the EU development program which has highlighted the rights of PwD. However, the focus of the Nordic neighbours seems to be shifting towards issues such as democracy/fighting corruption, peace and security, human rights defenders, gender equality and climate/environment issues. Disability is no longer mentioned as an issue on the web-sites of Norad and Danida, although they still have substantial support to disability programs. Norway adopted a plan of action in 1999 and guidelines on inclusion of PwD from 2002. Finland has traditionally been focusing on inclusive education programs. An evaluation of Finida’s disability programs was done in 2003. Danida is mainly involved in disability programs via DPOD (Disabled peoples organisations in Denmark), Norad is providing support through Atlas Alliance and Finland is mainly working through FIDIDA and Abilis Foundation.
To be successful in dialogue situations research and stakeholder analyses is necessary on the country specific context. Detailed tips and useful disability relevant information are available on the HRBA web-site for a number of sub-Saharan countries.

This paper outlines a broad policy dialogue based on the following dialogue strategy: make PWD visible in statistics – follow up on compliance in regards to human rights obligations – promote disability awareness and capacity development in all operations – support meaningful participation of PwD throughout the process – monitor for results. Below follows a list of suggested dialogue questions, guided by the international human rights treaties and based on the principles of participation, non-discrimination, openness and transparency and accountability. The questions may seem overwhelmingly many and detailed, and the idea is not to use them all, but those that are most suitable given the particular country context.

MAKE PWD VISIBLE IN STATISTICS

- Promote research on disability as well as capacity building in disability and data collection methodologies. It is important to point out that statistics should go beyond the issue of prevalence and also produce a poverty analysis. Development of disability data collection manuals, training materials and national action plans for improving disability information systems are useful tools
- Promote the integration of a disability perspective in national census and statistics (such as health surveys and poverty assessments) and that these contain disaggregated data on disability, so that poverty analysis, policy, planning, programming, budgeting and evaluation, better can incorporate disability dimensions and disability-sensitive measures.
- Promote dissemination of statistics regarding PwD to local level stakeholders for planning and monitoring.

FOLLOW UP ON COMPLIANCE IN REGARDS TO HUMAN RIGHTS OBLIGATIONS

- Monitor implementation of ratified human rights conventions, by follow up on the concluding observations in the Committees recommendations which come out of the presentation of State and Alternative reports. Reports are published on the website of the UN High Commissioner for Human Rights27:

27 http://www.ohchr.org/EN/HRBodies/Pages/HumanRightsBodies.aspx
• Promote independent structures to monitor the Convention on the Rights of Persons with Disabilities (CRPD) in accordance with article 33 (if ratified), to assist the ministries ensure that international agreements and monitoring reports reflect an accurate picture of the disability status.

• Make use of the Sida funded Disability Rights Promotion International’s, DRPI, project which has developed a specific model for monitoring rights of PwD, including policy monitoring, media monitoring and research on violations.

PROMOTE DISABILITY AWARENESS AND CAPACITY DEVELOPMENT IN ALL OPERATIONS

• Promote governments to increase disability awareness in general and invest in disability awareness trainings for local authority officials, administrators and field functionaries.

• Suggest governments to develop and disseminate policy and guidelines on disability inclusive development to ministries and local level authorities.

• Promote coordination across ministries: develop and implement strategies for coordination.

• Encourage capacity development of national and local Organisations of Persons with Disabilities (DPO) for participation at national and local levels.

• In donor community: promote the creation of multi-donor working groups on disability to harmonize donor actions. Many agencies now have formal commitments to include a disability perspective so that there should be an interest in joining such groups. Such groups could also provide awareness and training on disability-related issues and share best practices, information, tools and methodologies on the inclusion of a disability dimension.

• Encourage capacity development of national and local Organisations of Persons with Disabilities (DPO) for participation at national and local levels.

SUPPORT MEANINGFUL PARTICIPATION OF PWD THROUGHOUT THE PROCESS

• Support DPOs so that they can prepare themselves before going to meetings. Preparations should include analysis of the issues and papers at hand and training in constructive dialogue skills. Facilitate invitations and their inclusion in the process.

• Promote participatory methods in planning, implementation, monitoring and evaluation of national action plans and development initiatives, based on full and effective involvement of Persons with Disabilities. Meaningful participation requires accessible meeting halls and necessary services such as sign language interpretation, Braille material, guides (for blind persons) and personal assistants.
• Promote the establishment of channels for communicating between DPO’s and governments, including parliaments.
• Facilitate communication between agencies, stakeholders and DPO’s on disability issues (for example by organising round table meetings or by chairing meetings). Within the donor community: promote the establishment of formal processes for consulting the organisations.
• Encourage invitation of Organisations of Persons with Disabilities to influence PRS and sector processes and plans.

**MONITOR FOR RESULTS**

• Raise the issue of gaps between macro-level disability strategies and policies with micro-level disability action and point to the fact that macro- and micro levels need to be linked in monitoring.
• Promote earmarked budgets targeting disability in relevant sector programmes and schemes.
• Suggest that DPOs be involved in the monitoring process.
• Promote development of specific impact and outcome indicators for women, men, girls and boys with disabilities in PRS and sector programs (for example, literacy rate, school completion rates for girls and boys with disabilities, employment rate for PwD, access to credit and agricultural support measures, access to rehabilitation measures, health and HIV/AIDS programs, incidence of sexual abuse of women and girls with disabilities, access to medication for conditions such as epilepsy, mental illness etc.) and promote that baseline data is gathered for these indicators, preferably in collaboration with local universities, other research institutions and DPOs.
• Promote inclusion of PwDs in Terms of References for annual programme reviews and other monitoring, planning and evaluation processes.
PwD issues are of relevance in all contexts and sector programs. It is a critical issue in conflict/post conflict countries, where physical and psychological war related disabilities hinder peace and economic development, as well as in peaceful countries, where exclusion of PwD from PRS and sector programs hinders effective poverty reduction. The following sectors are of particular relevance to PwD.

**DEMOCRATIC GOVERNANCE AND HUMAN RIGHTS**

CRPD article 9, 12, 29, UN Standard Rule 18, Universal Declaration of Human Rights article 21, CEDAW article 7, 8, CRC articles 23.

**Critical issues**

PwD are frequently excluded from political processes and decision-making, including the fundamental right to vote or to be elected. This is often due to accessibility barriers, such as lack of accessible polling stations, material (for example in Braille), campaign literature, transportation to and from polling stations and postal voting. The exclusion is also caused by attitudinal barriers, preventing persons with disabilities from taking part in political processes. PwDs often have a very feeble voice or none at all in the democratic process. A lack of participation in the political debate results in policy being formed without the active involvement of groups likely to be affected by its outcome. Research, however, finds that capacity strong DPO’s can be quite effective in dialogue on national and local government levels. Hence, DPO’s need capacity development support, in particular to include more women and PwDs from rural communities in local level decision making and participation in the local development process. PwDs that stand for election and become appointed to public positions can provide an opportunity for effective promotion of the rights of Persons with disabilities. PwD are often denied equal recognition before the law. It is common that PwD are not considered to have legal capacity, and the practice of substituted decision-making, by family members, care-takers, institutions or others is common. Also, PwD lack equal access to justice. The judicial system is often affected by the same stigmas and attitudes that prevail in the society, and also legal procedures, practice and rules often do not take into consideration the needs for accessible information/communication, personal assistance, etc.

**Dialogue questions**

- Suggest that local authorities establish platforms for dialogue with local DPO’s.
sector programs where a PWD perspective is particularly relevant

- Promote capacity building of DPO’s to enhance their capacity to engage in public decision-making processes of all types.
- Encourage alliance-building between DPO’s, government structures, NGOs and the donor community, in order to include PwD in decision-making and development processes.
- Point to the need for information in accessible formats, such as Braille material and sign language.
- Point to the need for accessible meeting facilities to allow for inclusion of PwD.
- Raise the issue of legal capacity and access to justice: accessible information, asserting and safeguarding the legal capacities of PwD, and promoting modification and adjustments of legal procedures, with references to article 9 in the UNCRPD.
- Local voting procedures: are facilities and materials accessible to PwD? Suggest training of election officers on accessibility and disability awareness campaigns.

Indicators
The following indicators can be developed and used to monitor results.

- Number of elected officials with a disability.
- Number of consultations with DPO’s.
- Number of courts that recognizes and provides for alternatives modes of communication.
- Existense of national statistics on PwD.

infrastructure

CRPD article 9, UN Standard Rule 5, CRC articles 23.

Critical issues
Inadequate infrastructure causes major disabling conditions. Negative attitudes towards PwD is still the most fundamental barrier, but inaccessible environments, transport, technology, products and services also seriously limit the possibilities for PwD to participate in social and economic activities. Only few governments recognize the basic right of Persons with Disabilities to equal access to man-made environments and transport. Accessibility means making it possible to make use of the man-made environment or transports in an unassisted way. Transport systems that exclude PwD increase the risk that PwD will remain poor, because such systems may rule out education, prevent participation in the labour market, and restrict access to health care and other social services. The marginal costs of providing “access for all” features are much lower when incorporated into the original design and undertaken at the inception of the planning phase. Research indicates that providing full access facilities from the outset has an additional cost of approximately only 1%28. In many situations, low-cost improvements, such as curved insets at street corners, ramps to public buildings, and larger letters on bus destination signs can bring considerable benefits. The creation of a barrier-free environment requires the formulation of policy and legislative frameworks as well as the planning and implementation of accessibility strategies.

Dialogue questions

• Point to the need for accessibility standards when planning for public facilities, schools, infrastructure, and transport, including those in rural and agricultural contexts.
• Promote national and regional mechanisms to exchange information between governments, DPO’s, and professionals in architecture and engineering associations for accessible environments.
• Encourage universal design competences in academic curricula concerning professional education in architecture, building and engineering.
• Promote monitoring of compliance to existing accessibility legislation transports, public buildings and services.

Indicators

The following indicators can be developed and used to monitor results.

• Number of policies, projects and programs on infrastructure, transport, housing and services including targets or indicators on accessibility.
• Number of officials in the area of infrastructure development trained on accessibility.
• Number of times that DPO’s have been consulted in infrastructure development projects.
• Number of services and facilities made accessible (water, sanitation, electricity, housing schemes, health care, education etc.).

EDUCATION

CRPD article 24, Standard Rule 6, Universal Declaration of Human Rights article 26, CEDAW article 10, CRC articles 28 & 29.

Critical issues

UNESCO estimates that 90% of children with disabilities in developing countries do not attend school. UNICEF estimates that this figure is as high as 98%29. Even though school may be physically accessible, children with disabilities remain excluded. Inclusive education, with access to education in the regular local neighbourhood or community school, is more cost-effective than a complex system of specialized schooling for different groups of students and provides a better mainstreaming opportunity for the vast majority of children with disabilities, reaching children also in rural areas. A study carried out by the Organization for Economic Cooperation and Development (OECD) in 1994 showed that it can be between seven to nine times less costly to include students with special educational needs into regular schools, than having education in special schools. Various studies also showed that an inclusive education approach is more efficient as it improves school performance and the results obtained by all children30. Only in a few cases, when children have profound and complex difficulties or

sometimes when deafness without sign language opportunities may isolate a child in a regular class, may education in special schools be considered more appropriate. In order to be effective, inclusive education requires accessible facilities, appropriate teacher training, curricula development, provision of necessary devices and support services and accessible transportation. The issue of stigma attached to children with disabilities means that in many countries they aren’t registered at birth and therefore lack birth certificates and other necessary registration documents needed to access education\textsuperscript{31}. The involvement of parents and the local community is also key to promote education for children with disabilities, since many parents may fear that the child will not cope or that disclosure of a disabled child will stigmatize the family. Parental awareness is particularly important with regards to girls with disabilities. Girls with disabilities face multiple barriers in gaining access to schools and in obtaining an equitable education once they are enrolled in school. In most countries very little has been done to address education needs of girls with disabilities\textsuperscript{32}.

To allow for mainstreaming within the regular school, much can be done with rather simple means and without much additional costs. In addition to physical accessibility, the teaching methods used and the way in which the class room is arranged are of crucial importance. A positive attitude towards children with disabilities and a child-centred individualized approach that allows for children to learn at their own pace is important.

Dialogue questions
• Ask for earmarked budgets to be used for cost-effective measures to improve accessibility in schools (ramps, accessible latrines, Braille material, assistive devices, sign language trained staff and accessible transports and lodgings). And stress the importance of monitoring and responsibility for budgets.
• Point to the importance of awareness measures promoting positive attitudes towards children with disabilities among school staff, parents and communities.
• Promote inclusion and involvement of parents of children with disabilities in the educational process.
• Suggest that women and girls with disabilities are mentioned specifically in policy documents promoting educational equity for women and girls and in policies and programs designed to promote educational equity for children with disabilities.
• Suggest data collection on enrolment and completion rates among girls and boys with disabilities in primary and secondary education.
• Stress the need for appropriate teacher training, including in special needs education for inclusive education to be effective.
• Stress the need for children with disabilities to obtain birth certificates and registration documents which they need to access school.
• Ask about the supply and demand for vocational training opportunities for PWD. Ask if students are provided with the necessary work equipment that they need to use their skills.

\textsuperscript{31} http://www.unicef.org/media/media_43451.html
Children with intellectual disabilities: point to the need for assessment services that can properly assess their specific needs.

Promote inclusive education and “Education for all” instead of special education.

Enhance the development of flexible and relevant curricula, necessary in order to make inclusive education for all work in practise.

**Indicators**

The following indicators can be developed and used to monitor results.

- Enrolment and completion rates (percentage) for girls and boys with disabilities in primary and secondary schools.
- Number of physical improvements in schools to make them accessible, such as number of accessible classrooms and schools, number of accessible latrines built and adapted.
- Number of teachers trained in inclusive practices (e.g., training in Braille, in Sign Language, in disability-awareness and in the use of appropriate augmentative and alternative modes, means and formats of communication).
- Number of mainstream educational policies that specifically mentions children with disabilities.
- Number of assessment services and assessments performed that assess the specific needs of children with intellectual disabilities.
- Expenditures on the development of disability-adapted materials and development of curricula and amount of distributed training materials.
- Number of schools adopting flexible curricula for children with disabilities (allowing extra support and training for students with disabilities within school teaching).

**HEALTH**

CRPD article 25, UN Standard Rule 2, Universal Declaration of Human Rights article 25, CEDAW article 12, CRC articles 24.

**Critical issues**

PwD have the same needs for basic health services as everyone else. However, this need cannot always be met due to that health centres may be physically inaccessible and health workers may discriminate against Persons with Disabilities. Women with disabilities frequently complain of doctors denying them access to reproductive health services. Information on health care is often not provided in accessible formats and PwD are not targeted for health education. Some PwD have specific medical needs associated with their impairments. Persons with deafness report that their sign language interpreters are not allowed during doctors’ visits as a matter of confidentiality.

**Dialogue questions**

- Point to the need for physically accessible healthcare facilities and accessible information (Braille, sign language, radio, easy-to-understand materials) in health care issues, including reproductive health.
• Point to the need for increased disability awareness among health care workers, particularly in the area of sexual and reproductive health.
• Address the need for psychosocial treatments and rehabilitation.
• Point to the fact that some PwD lack birth certificates or other registration documents needed to access health care.
• Ensure access to social security systems.

Indicators
The following indicators can be developed and used to monitor results.
• Expenditure on making health services accessible to PwD: number of or percentage of health facilities accessible to PwD, spending on physical accessibility of buildings and services as a percentage of the national health budget, spending on adaptation of messages to ensure accessibility for PwD as a percentage of the national health budget, number of clinics that can service persons with deafness.
• Expenditure on training health professionals at all levels in disability related healthcare and rehabilitation: number of health professionals trained in disability awareness and ethical standards of care for PwD, spending on training of health staff on disability awareness as a percentage of the national health budget.
• Number of rehabilitation service centres that can be reached and accessed by PwD living in rural areas, number of objectives targeting rehabilitation for PwD in national health plans and budgets.
• In countries where disability disaggregated data is provided in health information systems: percentage of PwD with access to health care and programmes, percentage of women with disabilities with access to health care and services in the field of sexual and reproductive health, percentage of PwD with access to health-related rehabilitation services, percentage of PwD with access to assistive devices and technology, percentage of PwD with access to population based health programmes, number of children with disabilities with access to early identification, prevention and services designed to minimise the impact of disability.

HIV / AIDS


Critical issues
PwD are particularly affected by and vulnerable to HIV/AIDS. Information is rarely available in appropriate formats or adjusted to existing needs, taking into account accessibility and the high rate of illiteracy among Persons with Disabilities. There is a lack of information provided in sign language for deaf and hearing-impaired persons, in Braille for visually impaired persons and in any kind of accessible form for PwD with learning or intellectual disabilities. The discrimination against PwD manifests itself in numerous ways. HIV/AIDS education seminars are often held in buildings that are not accessible. Persons with deafness are often turned away from HIV/AIDS testing centres because nobody knows how to communicate with them. The sexuality
of PwD is something highly stigmatised and is therefore rarely discussed. PwD are wrongly presumed not to have sexual contacts, causing yet another reason why information about HIV/AIDS does not reach this group. Doctors are frequently reluctant to prescribe potent medicines to PwD for fear that they may not be able to follow instructions, read the labels etc. Many Persons with Disabilities are indirectly affected by HIV/AIDS since they are often dependent on their families and due to HIV/AIDS they risk losing the family who is assisting them.

Dialogue questions

- Demand that HIV/AIDS information, treatment and counselling is made available to PWD, with a specific emphasise on the need for sign language communication.
- Suggest that disability is included in prevalence studies by amending protocols and instruments used to determine prevalence rates.
- Promote that local health workers receives training in awareness of the rights of PWD and their different needs.

Indicators

The following indicators can be developed and used to monitor results.

- Number of physically accessible clinics and buildings.
- Number of health services that provides anti-retroviral treatments to PwD.
- Number of PwD with HIV infection receiving antiretroviral therapy.
- Number of health staff trained on disability and HIV/AIDS awareness.
- Percentage of HIV-infected pregnant women with disabilities receiving a antiretroviral prophylaxis to reduce the risk of mother-to-child transmission.
- Number of PwD that have participated in workshops on HIV/AIDS.
- Number of patients with disabilities with sexual transmitted infections at health-care facilities that have been diagnosed, treated and counselled.
- Number of organisations in the area of HIV/AIDS that specifically target PwD.

VIOLENCE AGAINST WOMEN AND GIRLS WITH DISABILITIES

CRPD article 6, 16, CRC articles 34, 39, UN Declaration on the Elimination of Violence against Women, 1993.

Critical issues

Violence against women and girls with disabilities is widespread and available data show that women and girls with disabilities experience more violence and abuse within the family, in institutions and in the community than their nondisabled peers. Sexual abuse is four times more likely among women with disabilities compared to their peers,

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33 Margaret A. Nosek, [http://www.bcm.edu/crowd/?pmid=1409](http://www.bcm.edu/crowd/?pmid=1409)
and it is especially common among women with mental and/or hearing disabilities\(^{34}\). Part of the explanation may be the disability limitations themselves make it more difficult for some women and girls to assess the situation, flee or defend themselves or to report incidents of violence. However, many agree that the most important factors are cultural and attitudinal. Women and girls with disabilities are often perceived as helpless, less valuable and powerless, and become an easy target. Power imbalances between PwD and their caregivers, isolation in homes or institutions away from public scrutiny and lack of education and training to help identify and address violence contributes to the high rate of violence. In addition, the police and community members may fail to respond appropriately to incidents of violence against women and girls with disabilities, doubting the credibility of the reporter\(^{35}\).

**Dialogue questions**

- Point to the fact that policies, legislation and programs related to violence prevention for women and girls should specifically address women and girls with disabilities.
- Promote specific research on the extent and nature of the violence that women and girls with disabilities face at home and in communities and schools, particularly in residential schools.
- Promote educational programs on violence prevention offered to women and girls with disabilities and their families.
- Point to the need for physical, cognitive and psychological recovery, rehabilitation and social reintegration for women and girls with disabilities that are victims of exploitation, violence or abuse.
- Inquire about the situation regarding institutionalization of PwD, especially women and girls with intellectual- and or psychosocial disabilities.

**Indicators**

The following indicators can be developed and used to monitor results.

- Number of studies about violence against women and girls with disabilities.
- Number of initiatives or policies on violence against women that specifically address women and girls with disabilities.
- The frequency by which facilities providing institutional living for PwD have been scrutinized by an independent monitoring body.

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Sida works according to directives of the Swedish Parliament and Government to reduce poverty in the world, a task that requires cooperation and persistence. Through development cooperation, Sweden assists countries in Africa, Asia, Europe and Latin America. Each country is responsible for its own development. Sida provides resources and develops knowledge, skills and expertise. This increases the world’s prosperity.