Training on the Inclusion of Persons with Disabilities in EU Development Cooperation

Course Notes

Module 1: Setting the stage: Why disability inclusive development and what does it mean?

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Introduction

The World Report on Disability published in 2011 estimates that one billion people in the world have some form of disability. This recognition that almost one in seven live with a disability reinforces disability as an important policy issue for governments, private sector and civil society. While there is no universally accepted definition of disability, over the past three decades there has been a significant change in how disability is understood from a policy perspective.

This module aims to give an introduction to disability by (1) introducing the different models of disability and linking them to Convention on the Rights of Persons with Disabilities (2) discuss issues impacting on the socio economic situation of persons with disabilities and the obstacles for measurement and finally (3) presenting key information and statistics from the World Report on Disability.

1. Different Models of Disability: From Charity to Rights

In answering the question ‘What is disability?’ there are a multitude of answers. The Convention on the Rights of Persons with Disabilities does not define disability rather under the purpose of the Convention is describes it as an ‘evolving concept’ including ‘those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.[1] The World Report on Disability describes disability as ‘complex, dynamic, multidimensional and contested’,[2] signifying that understanding what

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[1] See the Convention on the Rights of Persons with Disabilities, Article 1, purpose

[2] See the World Report on Disability (2011) Chapter 1 Understanding disability

it means depends on what perspective you come from. This perspective might be from a policy maker, lawmaker or disability advocate. This section highlights the evolution of the different models of disability which was traditionally understood within a medical/rehabilitative model to one which is now influenced by the Convention on the Rights of Persons with Disabilities and focuses on promoting and respecting the rights of persons with disabilities to live as equals in society.

1.1 The medical model:

Disability as a conceptual model over the decades has gone through a transformation. The early narrative on disability situated disability within medical, charity and personal tragedy models. As Simi Linton comments

> ‘[T]he medicalisation of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and significantly, as an individual burden and personal tragedy. Society, in agreeing to assign medical meaning to disability colludes to keep the issue within the purview of the medical establishment, to keep it a personal matter and ‘treat’ the condition and the person with the condition rather than ‘treating’ the social processes and policies that constrict disabled peoples lives’[3]

The medical model located the problem within the individual and persons with disabilities as deviant or not normal and constructed a medical and rehabilitation response to cater for their needs. In most cases this response was separate to mainstream public services and further contributed to the segregation of persons with disabilities from mainstream society e.g. through the establishment of specialist schools, institutions etc.

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[3] Simi Linton, Claiming Disability: Knowledge and Identity 11 (New York University Press 1998).

1.2 The social model of disability

The key elements of the social model lie with the belief that disability is not a biological construct; rather it is a social construct. Hunt and a cohort of UK academics Vic Finkelstein (1980), Colin Barnes (1991) and Mike Oliver (1990, 1981) succeeded in severing the causal link made between impairment and disability.[4] They succeeded in separating the individual's impairment as the cause of disability. Instead, they focused all solutions within the social model of disability. Hunt's famous quote on this is lengthy but worth citing

'In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairment by the way we are unnecessary isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this, it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability' of people with such impairment. Thus we define impairment as lack part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression' (UPIAS, 1976: 3-4)

Central to the social model of disability is the notion of creating a barrier free society through a range of different strategies, which include anti-discrimination laws, user led services and a strong disability movement.

1.3 The life cycle model/approach

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[4] See Thomas, Carol, How is disability understood? An examination of sociological approaches, Disability & Society, Vol 19, No 6, October 2004

The life cycle approach views disability as common part of the natural life-cycle. People with disabilities include those individuals who are born with and/or acquire physical, cognitive, or sensory impairments. Disability can result from malnutrition, lack of quality health care, including preventative medicine, chronic conditions, infectious diseases (including HIV/AIDS), ageing, injuries, disasters, conflicts and war, urbanization, pollution, environmental degradation, unsafe working conditions and poverty.

1.4. Rights-based Model

In essence, the social model of disability discussed in the previous section creates the foundation upon which a rights-based understanding of disability was built. The social model of disability is also one of the foundations upon which the Convention on the Rights of Persons with Disabilities (CRPD) was developed. A human rights-based approach sees people with disabilities as rights-holders, fully capable of participating in their life decisions and in society. The human rights framework, when applied to the specific situation of people with disabilities, defines limitations imposed by the social and physical environment in human rights terms and across a broad legal spectrum of civil, political, economic, social and cultural rights. One of the important points on the CRPD is that along with employment, education and housing rights, the CRPD also recognises the importance of health and rehabilitation to persons with disabilities. The CRPD fully recognizes medical treatment (under Article 25) as a necessary part of the rights people with disabilities should receive.[5]

2. Socio economic situation of persons with disabilities

People with disabilities tend to be marginalized in societies around the world.[6] They face large barriers in achieving active and meaningful

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[5] See the World Health Report (2011), which suggests that viewing disability as a human rights issue is not incompatible with prevention of health conditions.

[6] For more detailed discussion of the global situation of people with disabilities, see IDRM, *International Disability Rights Compendium* 2003 (Center for International Rehabilitation, 2003); National Council on Disability, *A White Paper: Understanding the Role of an International Convention on the Human*

participation in their communities. As the first UN Special Rapporteur on Disability observed:

> ‘[People with disabilities] frequently live in deplorable conditions, owing to the presence of physical and social barriers which prevent their integration and full participation in the community. As a result, millions of children and adults throughout the world are segregated and deprived of virtually all their rights and lead a wretched and marginal life.’[7]

2.1 Global Challenges to data and evidence collection on lives of persons with disabilities

At the outset it is important to recognise that comprehensive global data on the prevalence and socio-economic status of persons with disabilities while growing is still limited. This limitation occurs for a number of reasons, some of which include (1) variance in definitions and classification of disability and (2) lack of questions of disability in census collection and (3) limited data availability (particularly in developing countries) on areas outside traditional areas of governments measurement e.g. social protection and employment. Both these points are discussed in more detail below:

(1) Various reports have shown how the different classification systems and varying definitions of disability result in a challenge to the identification of persons with disabilities. Research conducted by the IDRM in Europe (2007) found that data on disability population varied from 4.5% (Armenia) to 18.2% (UK). This variance influenced by how disability is measured, for example in Armenia’s

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Rights of People with Disabilities (Washington, DC: June 12, 2002); Ann Elwan, *Poverty and Disability: A Survey of Literature*, WORLD BANK SOCIAL PROTECTION DISCUSSION PAPER NO. 9932, iv (Dec. 18, 1999).

[7] Leandro Despouy, Special Rapporteur, *Final Report*, U.N. Doc. E/C4/Sub2/1991/31 at ¶ 3 (12 July 1991).

measurement was carried out by an expert medical agency and the UK through its national census which features self disclosure of disability.[8]

(2) Omission of disability from Census and other official methods for collecting data. It is accepted that population-based data on disability is often lacking or inadequate in many developing countries. One of the reasons for this is that a question on disability is often not included in official measurements. For example, a number reports published by the International Rights Monitor on the Americas (2004) and Asia (2006) found that a question on disability was not included in countries like Cambodia and Vietnam and in cases where there was a question such as China, the information had gone for longer than 10 years without update.

(3) Narrow focus of collected data. Where data on the socio economic status of persons with disabilities does exist, it usually is limited to the context of a government's allocation of social protection or counting employment/unemployment and does not drill down further into other indicators of standards of living. More recently though, some progress has been made to gather data/indicators on a global level on other aspects of a person's with a disabilities status within their community. These indicators are influenced by the various articles of the Convention on the Rights of Persons with Disabilities. See Box 1 on the areas covered by the ESSL Social Index

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[8] For further discussion, see the International Disability Rights Monitor for Europe 2007)

Box 1: The ESSL Social Index 2011[9]

The focus of the ESSL social index is collect annual data that is comparable across a wide range of countries on different articles of the Convention on the Rights of Persons with Disabilities. The data collected aims to give both quantitative and qualitative data on the legal situation and living condition of persons with disabilities.

The 2012 report covered 36 countries and the forthcoming 2013 report will focus on including developing countries. Some of indicators collected as part of this report for 2012 were:

1. Accessibility of buildings
2. Right to primary mainstream education
3. Right to sign language in court
4. Availability of official statistics about education and employment
5. Right to marry and have a family
6. Accessibility of medical practices
7. Financial support for inclusion in the community (e.g. existence of independent living supports)
8. Availability of statistics of university graduates with disabilities
9. State employment of persons with disabilities
10. Existence of early warning system for national emergencies

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[9] See the Zero Report,

3. What evidence we do have on socio-economic status of persons with disabilities

As discussed in Section 2.1 there are a number of obstacles to collecting data on disability, particularly data which gives us indication on the lived experience of persons with disabilities.

In terms of socio economic status of persons with disabilities, the World Report on Disability (2011) compiled evidence across a wide range of areas (across both developed and developing countries) related to poverty, education, health and employment status. The following are a summary of its key findings:

- Across all countries, vulnerable groups such as women, those in the poorest wealth quintile, and older people had higher prevalence's of disability. For all these groups the rate was higher in developing countries. The prevalence of disability in lower income countries among people aged 60 years and above, for instance, was 43.4%, compared with 29.5% in higher income countries.[10]
- Evidence on poverty as measured by per capita consumption expenditures is also mixed. An analysis of 14 household surveys in 13 developing countries found that adults with disabilities as a group were poorer than average households. However, a study of 15 developing countries, using *World Health Survey* data, found that households with disabilities experienced higher poverty as measured by non health per capita consumption expenditures in only 5 of the countries[11]
- The *World Health Survey* cited in the World Report found that disabled respondents in 31 low-income and low middle-income countries spend 15% of total household expenditure on out-of-

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[10] See the World Report on Disability

[11] Mitra S, Posarac A, Vick B. *Disability and poverty in developing countries: a snapshot from the world health survey.* Washington, Human Development Network *Social Protection*

pocket health care costs compared with 11% for nondisabled respondents.

- In terms of education, respondents with disability in the *World Health Survey* experience significantly lower rates of primary school completion and fewer mean years of education than respondents without disability. For all 51 countries in the analysis, 50.6% of males with disability have completed primary school, compared with 61.3% of males without disability. Females with disability report 41.7% primary school completion compared with 52.9% of females without disability. Mean years of education are similarly lower for persons with disability compared with persons without disability (males: 5.96 versus 7.03 years respectively; females: 4.98 versus 6.26 years respectively).

- Children with disabilities are less likely to attend school, which in turns decreases their chances of developing skills for future employment opportunities[12]. This pattern of non-attendance is more pronounced in poorer countries.[13] The gap in primary school attendance rates between disabled and non-disabled children ranges from 10% in India to 60% in Indonesia, and for secondary education, from 15% in Cambodia to 58% in Indonesia[14]

- People with disabilities are more likely to be unemployed and generally earn less even when they are employed. As severity of disability increases, employment and income outcomes worsen and finally, it is much harder for people with disabilities to benefit from development and escape poverty due to discrimination in employment, limited access to transport, and lack of accesses to resources to promote self-employment.[15]

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[12] See Filmer D. Disability, poverty and schooling in developing countries: results from 14 household surveys. The World Bank Economic Review, 2008,22:141-163. doi:10.1093/wber/lhm021, see also Burchardt T. The education and employment of disabled young people: frustrated ambition. Bristol, Policy Press, 2005.

[13] See *Education for All Global Monitoring Report*. Paris, United Nations Educational, Scientific and Cultural Organization, 20

[14] See Table 7.1 on Education Outcomes for disabled and non disabled respondents, pg.207, Chapter 7, World Report on Disability (2011)

[15] See Coleridge P. Disabled people and 'employment' in the majority world: policies and realities. In:

Analysis of the World Health Survey results for 51 countries gives employment rates of 52.8% for men with disability and 19.6% for women with disability, compared with 64.9% for non-disabled men, and 29.9% for non-disabled women.

- People with disabilities may have extra costs resulting from disability – such as costs associated with medical care or assistive devices, or the need for personal support and assistance – and thus often require more resources to achieve the same outcomes as non-disabled people.

Roulstone A, Barnes C, eds. *Working futures? Disabled people, policy and social inclusion*. Bristol, Policy Press, 2005.