Disability and Human Development: Theories for Practice

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ABSTRACT

This paper compares changes in the understanding of disability and human development, discusses the result of a global study of the relation between the Human Development Index (HDI) and disability prevalence, and explores the relevance of current theories for sustainable human development in the field of disability.

The fields of disability and human development have become more holistic in their understanding of their respective key issues. General principles of and strategies for sustainable human development are applicable to all people, including people with disabilities. However, a limited number of the strategies need to be elaborated and specified to ensure sustainable inclusion and participation of people with disabilities in society and its development.

Introduction

> The basic purpose of development is to enlarge people's choices. … The objective of development is to create an enabling environment for people to enjoy long, healthy and creative lives. (Haq 1995)

This quotation points out two important aspects of development; *enlarging people's choices* and *creating enabling environments*. The focus of 'enlarging people's choices' is the needs and interests of individuals, while 'creating enabling environments' focuses on the environment of these individuals. Readers familiar with the discourse in disability recognises that individual persons and their environments are key components of contemporary understanding of disability.

This paper attempts to identify basic similarities between the fields of disability and human development and to explore how basic principles of and strategies for human development can be applied in the field of disability.

Changes in the understanding of disability and human development

The understanding of the concept of disability varies. It can vary between cultures and evolve within a culture over the years. Different cultures may have different expectations, e.g. for functioning based on age and gender (Üstün *et al*. 2001).

Breslin (1998) describes four disability paradigms[1]: the moral, the medical, the civil rights, and the post-modern. In the moral paradigm the individual with a disability is viewed as a sinner with a moral or spiritual problem. In the medical paradigm the individual with a disability is considered as a beneficiary of professional treatment and services. The civil rights paradigm changes the focus from the individual to the society – the problem lies in the society's response to people with disabilities, and its systems, laws, policies and relationships. The understanding in the post-modern paradigm is that the society's economic policies and priorities, as well as a widespread acceptance of the medical model's influence and assumptions, cause the problems experienced by people with disabilities. The civil rights and post-modern paradigms on the other, are commonly referred to as the "medical model" and the "social model", respectively.

In the International Classification of Functioning and Disability (ICF) the medical model is described as follows:

> The medical model views disability as a problem of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. Management of the disability is aimed at cure or the individual's adjustment and behaviour change. Medical care is viewed as the main issue, and at the political level the principal response is that of modifying or reforming health care policy. (WHO 2002)

Mercer (2002) argues that the medical model underpinned a system that condemned people with disabilities to the status of second-class citizens, characterized by wide-ranging social exclusion from mainstream society and segregated living in residential institutions. In the 1960's and 1970's, British and North American individuals and groups began to oppose disability as a purely medical and welfare concern and reformulate disability as a form of social oppression (Mercer 2002, Thomas 2002). ICF describes the social model in this way:

> The social model of disability … sees the issue mainly as a socially created problem, and basically as a matter of the full integration of individuals into

[1] In this paper 'paradigm' and 'paradigm shift' refers to 'thought-pattern' and 'change of thought-patterns', respectively, which may differ from the scientific meanings of the terms.

> society. Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence the management of the problem requires social action, and it is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life. The issue is therefore an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights. For this model disability is a political issue. (WHO 2002)

In the revision process of the first WHO International classification of impairment, disability and handicap (ICIDH) (WHO 1980), it was decided to base the new classification ICF on an integration of the medical and social model, called a "biopsychosocial model". ICF attempts to provide a coherent view of different perspectives of health from three different perspectives: biological, individual and social. It was also decided that ICF should not be a classification of functional problems that people may experience. Rather ICF should be a universal classification of human functionality itself at three levels, which were labelled body functions and structures, activities, and participation. By doing so, the term disability was freed from its association with person level functional problems. Hence, WHO decided to use "disability" as an overall term in ICF for the three levels of functional difficulty (Üstün et al. 2001). The understanding of disability from only being related to the person, as in ICIDH, was changed, and WHO now relates disability to the body, the person and the society.

In ICF, disability is thus used as an umbrella term for impairment, activity limitation, and participation restriction. Impairments are problems in body function or body structure. Activity limitations are difficulties an individual may have in executing a task or action. Participation restrictions are problems an individual may experience in involvement in life situations. The disability may be influenced by contextual factors, which represent the complete background of an individual's life and living. The contextual factors include environment factors and personal factors. The environment factors make up the physical, social and attitudinal environment in which people live and conduct their lives. The personal factors comprise features of an individual that are not part of a health condition or health states, e.g. gender, race, age, lifestyle, social background, education and profession. Complementing the term 'disability', 'functioning' is used to indicate non-problematic aspects of health and health-related states. (WHO 2002)

Every person has a right to development. In the Declaration on the Right to Development (UN

1986) the component rights include rights to participation in development, the right to non-discrimination in development, the right to self-determination, and the right to free and complete fulfilment of the human being.

Like the understanding of disability, the perspectives on development have changed over the years (Jahan 2002). A paradigm shift occurred in 1990 when the concept of human development was introduced and presented in the Human Development Report. Before 1990, development had mainly been perceived in economic performance and measured by per capita income. But Nobel laureate Sen (1989) pointed out that countries with high Gross National Product (GNP) per capita can have low achievements in the quality of life. There are many examples of countries with a lower literacy rate, a higher infant mortality rate, or a lower life expectancy, respectively, than countries with a lower per capita income (Haq 1995). To be able to evaluate development beyond GNP per capita, Sen (1989) introduced the "capability approach". The capability approach sees human life as a set of functionings, e.g. escaping morbidity and mortality, being adequately nourished, achieving self-respect, and taking part in the life of the community. A functioning is an achievement of a person: what he or she manages to do or to be. Based on this understanding of functioning, capability reflects the various combinations of functionings a person can achieve, i.e. a person's freedom to choose between different ways of living.

Haq (1995) states that the defining difference between the economic growth and human development schools is that economic growth focuses only on one choice – income, while human development focuses on all human choices – whether economic, social, cultural or political. The basic purpose of development is to enlarge people's choices, and the objective is to create an enabling environment for people to enjoy long, healthy and creative lives. The human development paradigm covers all aspects of development, including economic growth. However, economic growth becomes only a subset of the human development paradigm. (Haq 1995)

A few recent studies have been undertaken to compare the capability framework and different models of disability (e.g. Burchardt 2004, Mitra 2006, Terzi 2004). Without going into details of different ways to relate the capability approach and the ICF model to each other, the terminology introduced by the ICF and the capability approach makes it possible to understand 'functioning' as used in ICF as an aspect of 'capability', and 'disability' as an aspect of 'capability failure'. As 'development' can be seen as an 'expansion of capability', 'improved functioning' would then constitute 'development' (Qizilbash 2006). Hence, it can

be concluded that activities aiming at improving functioning of people with disabilities, whether related to body functions or structures, activities or participation, can be regarded as development activities.

Human Development Index (HDI) and disability prevalence

The new understanding of human development lead to the need for a measure to evaluate socioeconomic progress of nations; a measure that could be used to evaluate development in terms of all, or many more, of the choices people make. According to Haq (1995) these "choices covered the desire to live long, to acquire knowledge, to have comfortable standard of living, to be gainfully employed, to breathe clean air, to be free and to live in a community." It was clear that not all these choices could be measured. However, the measure should cover both social and economic choices.

To be able to measure human development beyond per capita income, the Human Development Index (HDI) was developed and used in the Human Development Reports of UNDP starting from 1990 to rank the countries of the world. The HDI gives equal importance to a long and healthy life, knowledge, and a decent standard of living (measured in GDP per capita). The introduction of the HDI has lead to a broader view of development.

Considering the developments in the fields of both human development and disability, and in a response to the need for mapping the situation of people with disabilities in the world, Borg (2006) undertook a study with an objective to explore the relation between the HDI and the disability prevalence in a global perspective. Data on human development and disability prevalence of 107 countries were gathered and analysed. The findings indicated a positive relationship between the HDI and its sub-indices[2] on the one hand, and reported disability prevalence on the other. The strongest correlations with reported disability prevalence were found for the Gross Enrolment Ratio (GER) Index and the GDP Index.

At a global perspective the findings can not be used to support the fact that poverty is a cause of disability – then the disability prevalence would be high in countries with low GDP – or that disability causes poverty – then countries with a high disability prevalence would have a low GDP.

Why is it then that disability prevalence is low in countries with low HDI and high in countries with high HDI? One reason that may explain this is that the methods and definitions to identify people with disabilities differ between countries resulting in different prevalence

[2] HDI sub-indices: Life Expectancy Index, Education Index (which is based on Gross Enrolment Ratio Index and Adult Literacy Index) and GDP Index.

rates. Another reason could be that people in countries with high GDP and relatively generous social security can financially and socially "afford" to be identified as having disabilities (Larsson 2001).

As pointed out, the strongest correlation was found between disability prevalence and the Gross Enrolment Ratio Index. A high enrolment ratio means that more children attend school. More children attending school may imply that more children with disabilities attend school, which could indicate a society where disability is more recognised.

The study did not rank the importance of the different indices with respect to disability prevalence. However, a final observation that can be made is the positive relationship between life expectancy and disability prevalence. This means that the disability prevalence is high in countries where people live long; a finding which is probably explained to a large extent by the results of demographic studies concluding that disability prevalence increases by age (Kraus *et al.* 1996, NYSDOH 2001).

Sustainable human development and people with disabilities

The classical approach to development was based on three factors of production: land, capital and labour (human beings). Sustainable development on the other hand consists of the two components 'sustainable human development' and 'environmental sustainability'. Sustainable human development has moved the emphasis from the material well-being of states to the well-being of individual human beings. (Hasegawa 2001) Sustainable human development has been described in the following way:

> …development that not only generates economic growth but distributes its benefits equitably; that regenerates the environment rather than destroying it; that empowers people rather than marginalizing them. It gives priority to the poor, enlarging their choices and opportunities, and provides for their participation in decisions affecting them. It is development that is pro-poor, pro-nature, pro-democracy, pro-women and pro-children. (Taylor-Ide, Taylor 1995)

While protecting the natural systems – on which we all are dependent – sustainable human development aims at expanding the choices of all people, including current and future generations. Placing people at the core and viewing people as both a means and an end of development, sustainable human development aims at eliminating poverty, promoting dignity and rights, and providing equitable opportunities for all. (UNDP 1998)

Taylor-Ide and Taylor (1995) have suggested three basic principles of sustainable human development.

1. Sustainable human development evolves from a self-reliant understanding of local needs and resources.
2. Action must grow from a combination of bottom-up and top-down programming.
3. Sustainability is possible only when action grows from community participation and self-reliance.

According to Haq (1995) there are four ways to create desirable links between economic growth and human development.

1. Investment in education, health and skills can enable people to participate in the growth process and share its benefits.
2. Equitable distribution of income and assets.
3. Well-structured social expenditures on social services.
4. Empowerment of people, particularly women. There is a good chance that growth will be strong, democratic, participatory and durable if people can exercise their choices in the political, social and economic spheres.

All people, including people with disabilities, are included among the stakeholders of sustainable human development. In addition to the development areas described above, and as pointed out earlier, improving functioning of people with disabilities is development. This development can be related to a person's body functions and structures, her or his execution of tasks or actions (activities) and involvement in life situations (participation). The purpose of using body functions and structures as well as executing tasks and activities is often to be involved in life situations, i.e. participation. An important aspect of sustainable human development for people with disabilities would therefore be to improve their participation. This can be achieved by improved body functions and structures, alternative techniques to carry out tasks and activities, and by removing barriers and introducing facilitators in the environment, which includes the physical, social and attitudinal world (WHO 2002).

Human development aims for people to enjoy long lives. As noted earlier, when people grow old they become increasingly disabled. It is therefore unlikely that it is possible to improve body functions and structures throughout life. Instead, over the years focus may increasingly need to be on introducing facilitators and removing barriers in the environment in order to improve or sustain a person's level of participation. This raises demands on countries with aging populations.

Particular requirements to ensure sustainable inclusion of people with disabilities are

(Wiman *et al.* 2002, WHO 2001):

- mainstreaming of physical environments, products and services are made accessible, i.e. they are designed for all,
- barrier-free social and attitudinal environments, i.e. they are inclusive,
- general services and systems, such as housing, health care, transportation, schools and income generating activities, are made accessible, and
- specific services and systems, such as medical treatment, rehabilitation, assistive devices, and support services, are made accessible and affordable.

Conclusion

The understanding of human development and disability has evolved over the years in ways that remind of each other. Like rising incomes is no longer seen as an end but a means for development, improved body functions is no longer seen as an end but a means for participation. Development is no longer measured in GDP only, but also in life expectancy and education. Similarly, disability is no longer an attribute of an individual, but an umbrella term for impairments, activity limitations, and participation restrictions. Despite completely different starting points – a single characteristic of a nation in the development discourse and a single characteristic of an individual in the disability discourse – the changes in the understanding of development and disability have lead to a holistic perspective on individuals where the social and economic environment plays an important role.

Relating disability prevalence to the current measure of human development HDI reveals a positive relationship. The positive relationship between disability prevalence and life expectancy is in harmony with earlier research that has found that disability prevalence increases by age.

All people are stakeholders in sustainable human development. Principles and strategies are equally applicable to people with disabilities. Investments in education, health and skills, equitable distribution of income and assets, well-structured social expenditures and empowerment of people are important to all. Development needs to be of all people, for all people and by all people.

With the current understanding of human development, activities aiming at improving functioning of people with disabilities can be regarded as development activities. Therefore, equitable activities for sustainable human development can not afford to exclude necessary activities for people with disabilities. These activities include improving body functions and

structures, offering alternative techniques to carry out tasks and activities, and removal of barriers and introduction of facilitators in the environment.

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