

DISABILITY COMING ON THE FRONT-LINE IN DEVELOPMENT

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In this article, I describe the current international trends and the achievements of the disability movement during the past few years. This article focuses on the role of various UN bodies and development banks. There is not so much discussion on the activities of governmental development agencies or developing organizations of disabled people. These issues are also very important and should be given thorough consideration at some later stage.

We have found it difficult to bring disabled people on the front-line in any of development agencies or governmental policies. Organizations of disabled people have tried to get issues on different agendas, but the work is difficult.

In United Nations, there is nowadays a panel of Experts which supports special rapporteur Bengt Lindqvist in his challenging work. The panel has members from different International Organizations of disabled people and Rehabilitation International. Mr. Lindqvist is reporting to the ECOSOC annually. This arrangement is valid until the end of year 2000.

General Assembly has discussed every year a report concerning the issues of disabled people but in the reality very few things has happened. There are lot of good wishes and lip service but practical actions on the part of the UN are virtually non-existent.

In fact, the different UN bodies like UNDP, ILO, WHO etc. UNDP could be the focal point for all activities. UNDP has had some projects on rehabilitation, but we have not seen mainstreaming or an approach that is based on equalization of opportunities.

UNDP has representatives in all developing countries. They are also a major source of funding. They have on-going dialogues with local governments but not so much with any NGO's, not to speak organizations of disabled people. Most local authorities have little interest on disabled people; they are on priority list place 271. Even those governments who are interested in social issues tend to think of able-bodied people only.

Most of the organizations of disabled people are rather weak. Their membership is limited and they have little mental or material resources. This is a part of the development stage of the country. In practice, this means that these organizations are not able to contact UNDP, present different strategies or plans and raise their issues on the agenda. This is why the initiative should come from the UNDP: they should start a dialogue with organizations of disabled people.

This means that the UNDP could organize training for disabled people and their organizations on development issues. This should cover such issues as the activities of UNDP; the actions of authorities on development issues in the country in question; what development means; what is the role of civic society and an NGO; how to interpret a problem into development action etc.

UNDP has to create a policy where disability is an integral part of its activities. This policy should pay attention to the specific problems of disabled people. The policy must be created on the top level, where government representatives are making decisions and then it should be implemented on the national level.

Naturally, we must not forget the role of other UN bodies. Some of them have had, in the past, programs for disabled people, for instance ILO. The ILO does have a unit for disability issues; unfortunately, the unit is quite small and does not have much resources. The main problem is that since the formation of this unit, other parts of ILO have left disabled people off the agenda – after all, they are already taken care of. This is a danger that a special unit brings with it; but at the same time, if there is no unit it may happen that nobody takes care of disabled people. This is an issue which must be identified and avoided by the main leadership.

Mainstreaming and cross-cutting disability is, in the end, the right philosophy but this can be also pushed with special units if the units are not too isolated. This means that the units have a mandate to cooperate with other parts of the organizations. This requires that there is ongoing dialogue with the units and organizations of disabled people.

This on going cooperation becomes increasingly more important. There have been meetings and seminars with different UN organizations one by one, but what we need now is regular meetings with an agenda. We need to discuss different issues and the organizations need to listen to what NGO's have to say. With this approach, it is possible to raise the activities of the UN organization to new levels.

The Banks

The role of World Bank and regional development banks is becoming more important in future. There have been activities with World Bank to sensitize it to disability issues. Disabled Peoples' International had three visits with the Bank during my chairmanship. The atmosphere was very positive in all of them and we saw some good initiatives.

The World Bank now has a handful of people working on these themes and they begin to take these issues into consideration in their everyday work.. They do not yet have a policy and their initiatives have remained somewhat isolated. There is the possibility, however, that they will later put on an agenda with discussion especially on social, health and education projects and issues related to disability.

World Bank like other development banks are – Banks: they do not donate funds, but they lend money to governments. These institutions have been strongly criticized earlier for concentrating on hard values such as roads, factories and economical growth. Today, however, they have changed their policies considerably, and started to support soft sectors like education, health care and social development. These sectors are a prerequisite to economical growth.

I have been working also with Inter-American bank and Asian Development Bank during the last year. Just recently I participated in the ADB workshop entitled Development and Disability in Manila. This workshop was done together with DPI, other NGO's and the Bank. Finnish government supports this activity and values it highly.

The bank is opening new horizons when it starts direct discussions with disabled people in the region. Hopefully, it will help NGO's to participate in the development processes in the region and in different countries. The ADB will have direct information and it will help them to further develop their own activities. During my first visit to Manila some years ago, I realized that there is an interest to include disabled people in different development processes but there is not necessarily a vision on how to do it.

The vice-president of the ADB Peter H. Sullivan spoke in this seminar about poverty and disability: "During the 32 years that the ADB has been in existence, the focus of our operations has shifted from funding physical infrastructure to supporting more broad based development. With its overarching objective of poverty reduction, the bank's goal must be to bring more and more people into the economic

mainstream, to promote equitable access to the benefits of development regardless of nationality, race, gender or disability. This - the challenge of inclusion - is the key development challenge of our time.”

"Poverty reduction and improving the quality of life of all people in the Asia and the Pacific has become the overarching objective of the ADB. The Bank will focus all its activities more clearly to meet this goal. Social development has been and continues to be one of the key objectives of the Bank. It has been recognized a key area for poverty reduction together with the pro-poor, sustainable growth and good governance" (Anita Kelles-Viitanen, ADB)

As a result of this workshop, disability is now part of the poverty reduction strategy. The workshop made a number of recommendations to the ADB, for instance that they should acquire expertise on poverty and disability, maintain an on-going dialogue with the organizations of disabled people etc. The ADB directors reacted quite positively to these ideas. I am sure that in future disabled people will be better recognized in the activities of the bank.

Disability and poverty is a very important issue in Asia. We are all aware that poverty creates disability and disability creates poverty. Disabled people are poor in the sense of missing economical resources but also other resources such as education and training.. This is also the case in other parts of the world.

The Organizations of Disabled People (ODP) must learn how to cooperate with the banks. This requires training in the national, regional and international level. ODP's have to learn to influence the strategies and policies and not only to look at their own projects in a short perspective. If disability is included in the activities of the bank, this will result, at a later stage, in easier access to funding for the organizations themselves.

Nordic activity

Next, I would like to comment on the recent developments in Nordic countries. Here, ODP's interested in development cooperation have met regularly last ten years. The last two years have seen government representatives entering these discussions. We have had a series of workshops during Autumn 1999 in different Nordic countries to deepen the discussion. In the year 2000, there will be a conference where we try to find a joint Nordic policy and approach to disability and development issues.

In Finland, we organized a workshop on multilateral cooperation. When I write this the recommendations are not yet finalized but these are some of the themes:

All development programs and projects should be screened for their disability relevance to ensure that the outcome is barrier-free and not handicapping

All mainstream activities that are highly relevant for disabled people should be planned with the intensive involvement of disabled people. All activities within the planned health, welfare, education, housing and employment sectors should belong to this category.

The ownership of the projects targeted specifically to people with disabilities should be handed over to people with disabilities themselves. Best practices and success stories promote further success and should be shared as common property within the all interested.

The idea is that Nordic countries will, in future, raise disability issues on the agenda in all multilateral forums. We are working quite closely and rotating representatives in decision-making bodies. The preliminary results of analyses of these international bodies show that there is a lot of work to do. Disabled people are not prioritized and very often forgotten.

Some of my friends in Bosnia told me that Bosnia has received a fair share of funding, but very little of it has been given to disabled people. What is more, most of the old barriers have been built again in the reconstruction process, and barrier-free constructions are very rare.

After this Nordic cooperation, the next step is to see if we could find a joint approach in OECD, which involves major EU countries, USA, Canada and Japan. If these major donor countries could find a policy where disabled people are included, we could see real change. But this requires a lot of work and cooperation between NGO's in these countries.

Of course, disability and development is not driven by western well-developed countries but it is our duty that our governments start inclusion. The next step is that the priorities in developing countries are done by disabled people in these countries with their governments.

Activities in Finland

In Finland we have been working actively with the Ministry of Foreign Affairs and its Department for International Development Cooperation (Finnida). We have nowadays a joint working group to discuss Finnida's activities and how disability could be mainstreamed. The spirit in this group is very good and there will be changes in Finnish development cooperation policy. Some years ago, the Finnish government gave a statement in principle saying that disability is one priority area of activities in the field of poverty eradication. This was a major step towards renewing development cooperation.

As a part of this process, the National Research and Development Centre for Welfare and Health (Stakes) has created by Ronald Wiman a Rapid Handicap Analysis of Development Activities. This is a 10-point checklist to facilitate the rapid assessment of development programs and projects for the adequate inclusion of the disability dimension in the plans.

There is also a new instrument for development cooperation called Abilis Foundation. The purpose of this foundation is to give micro grants for disabled people and their groups or organizations in developing countries on the grass roots level. The maximum grant is US\$ 10.000. The foundation gives grants only to organisations run by disabled people themselves. The Ministry of Foreign Affairs has made a three year contract with Abilis Foundation so that here is US\$ 1.000.000 available for this foundation each year. This is a totally new form of funding and during the first year there have been already more than 100 applications. The Abilis Foundation enables us to minimize bureaucracy and give support directly to disabled people on the grass roots.

Conclusion

Disability is coming increasingly on the front line of development activities but we still have a lot of work from charity to equal participation and human rights. This demands that we all work together and listen to the voices of disabled people in developing countries.

DEVELOPMENT AND DISABILITY

There are disabled people the world over. There is not a village or town without population with disabilities. Many estimates have been made of the number of disabled people in the world and of what the main disabilities are in different parts of the world. But, although this statistical information is

interesting, it is not of great importance now. What is important is that there are a great number of disabled people living in developing countries under very different circumstances.

The UN World Program of Action Concerning Disabled Persons (WPA) states:

“More than 500 million people in the world are disabled as a consequence of mental, physical or sensory impairment. These persons are entitled to the same rights as all other human beings and to equal opportunities. Too often their lives are handicapped by physical and social barriers in society which hamper their full participation. Because of this, millions of children and adults in all parts of the world often face a life that is segregated and debased.” (WPA p.1).

“It is estimated that more than one person out of ten is disabled by physical or mental or sensory impairment, and at least 25% of any population is adversely affected by disability. At least 350 million disabled persons are living in areas where they do not receive the services needed to enable them to overcome their limitations.” (WPA p.11).

“In addition, disabled people are the poorest of the poor. They do not often have access to adequate medical services. As a result, disabilities are often not detected in time to minimize their effects. By the time medical attention is given – if it is given – impairment may have become irreversible.” (WPA p. 13-14).

In the last ten years disabled people have set up their own organizations in some 130 countries. Disabled people’s organizations are defined as those controlled by a majority of disabled people (51% or more) at the board and membership levels. The World Programme of Action (WPA) states in paragraph 28:

“The role of these organizations includes providing a voice of their own, identifying needs, expressing views on priorities, evaluating services and advocating change and public awareness. As a vehicle of self development, these organizations provide the opportunity to develop skills in the negotiation process, organizational abilities, mutual support, information sharing and often vocational skills and opportunities. In view of their vital importance in the process of participation, it is imperative that their development be encouraged.”

What is the basic problem and what is the solution?

The tremendous problems which people with disabilities face daily just so they can survive are apparent, but nevertheless there is a of hope as well. Overcoming these problems will of course take time and effort.

The main problem is this: Are people with disabilities members of society or are they isolated and segregated?

The solution: The disabled individual’s own efforts to improve this state. This is not to say that other people are not needed – naturally people with disabilities need support and help – but the key to change doesn’t lie there.

What is development?

A simple definition of the world “development” one which is both workable and meaningful, must first be established. The specific elaboration of this term must be understandable and acceptable to

organizations of disabled people. This definition should essentially contain the principles of participation and self-help, principles which put **people** at the front of the development process. The definition should emphasize ability rather than disability, and the human element must not be forgotten.

There are various approaches to this question:

1. Development can only be seen as a dynamic dialectical process. In some situations it retrogresses – creating underdevelopment. In other it progresses, bringing about improvement and in the conditions of life.
2. A state of underdevelopment can be recognized when people are not in control of their own lives, i.e. when a state of dependency exists.
3. Development can also be interpreted as liberation. A development organization should foster enablement, empowerment and liberation. In regard to disabled people development could mean liberation from community and institutional oppression, as well as liberation from hunger and poverty.
4. People can only liberate or develop themselves if they are able to identify the forces that constrain or oppress them, the forces which leave them in a state of underdevelopment and disamination.

Disability policy must attack the total situation, not just disability issues. People with disabilities are complete and whole – total human beings: the organizations of the disabled should be geared to examining the whole situation and evolving development strategies that deal with it.

The policy must identify people with disabilities as an oppressed minority. The degree of oppression that affects disabled people varies from society to society and people with certain disabilities experience a more extreme form of oppression than others. The development policy must accordingly address the issue of liberation.

Public attitudes are continually being cited as the greatest single factor affecting the development and liberation of people with disabilities.

The development policy must be a positive policy that avoids apologizing for disability and does not substitute half-way measures and incompetent programmes for concrete action designed to tackle concrete situations. The policy must emphasize ability.

Dependence is symptom of underdevelopment. If one is dependent, one is not liberated. It is probably true that total liberation and total independence are not achievable; but people with disabilities have a right to as much independence as non-disabled people. Development policy should therefore foster independence and promote the provision of independent living and working programmes, especially when these are operated by the organizations of disabled people. The policy should encourage the control of those services by the users of such services. We must think seriously about what we mean by the control and orientation of rehabilitation including community based rehabilitation (CBR).

The problems of disabled people in development are also dependent on the definition of disability. This affects the policies both in developed and developing countries and hinders positive governmental activities in the area.

Historically the analysis of the situation of disabled people has been made from an individual perspective. The focus has been on the various limitations **in the individual**. The definitions should make it possible to analyze the various problems we face, keeping the focus on the various limitations **in**

society. Disability should be defined as a violation of human and civil rights of disabled people. Thus the definition is more political and social than medical as it has been so far.

In our common endeavour for full participation and equality for the world's disabled people, the following rights have fundamental importance.

The right to education
The right to rehabilitation
The right to employment
The right to economic security
The right to independent living
The right to participate in social, cultural and political activities
The right to influence

Development is organizing

Disabled People's International (A global organization of people with all kind of disabilities) has that philosophy that development is equated with organizing. This is the starting point and the method of development. People with disabilities have to come together and work together. This kind of approach presents certain challenges and requirements for the organizations of disabled people which want to promote development.

1. Organizations of disabled people should direct all their activities towards development. All other activities must be minimized. At all levels – grassroots, regional, national and international – people must work together with determination towards development.
2. Basic activities must take place at the grassroots level. All other activities must support the basic approach. Development is realized concretely where people are living. This grassroots development demands support from all levels of organization and from all levels of society.
3. Disabled people have to develop themselves.
4. Organizations of disabled people must create their own strategies for developmental circumstances.
5. Organizations of disabled people must work to ensure that other sectors of the society on local, regional and global levels create developmental situations for disabled people.
6. Organizations of disabled people must establish development policies as guidelines for themselves in future. These policies should include the activities of the organization itself as well as guidelines for other institutions.

Disabled people's organizations arise in response to our perception that we need to destroy those barriers which prevent our participation in society. These organizations are based on the needs and aspirations of the grassroots community of disabled persons. The disabled people who start such organizations are usually educated and better off financially than the majority of disabled persons in their countries. Their educational advantage allows these persons to identify and analyze the barriers that prevent people with disabilities from participating in society. They have learned the tools that the rest of society uses and they employ them to benefit off all disabled people, who in some developing countries are 99% illiterate. Furthermore, it is disabled people who must identify their own needs and how to meet them. Paulo Freire explains in *Pedagogy of the Oppressed*”:

“... those who recognize, or begin to recognize themselves as oppressed must be among the developers of the pedagogy. No pedagogy that is truly liberating can remain distant from the oppressed, treating them as unfortunates and by presenting for their emulation models from among the oppressors. The oppressed must be their own example in the struggle for their redemption.”

Democratic representation – which is a necessary element for development – provides indirect input. By definition, organizations of disabled people are controlled at the board and decision-making levels by disabled persons. People are elected to the decision-making bodies of organizations by their membership. Thus, the disabled people elected to the boards relay those people’s concerns to governments, service providers and the public. If it is not the case, development will be very difficult if not impossible to attain.

Where comes the development cooperation?

Development cooperation is a very important element in supporting disabled people in the development of their own activities and participation in society. There are some very important principles which should be in this process.

The principles are:

1. All development programs must include elements concerning disabled people.
2. All development agencies must include special programs concerning disabled people.
3. Disabled people’s organizations must be involved in planning, implementing and monitoring programs or parts of programs concerning disabled people.

These principles were in fact approved in a UN experts meeting (Beijing 1990). If they were used in practice the change would be remarkable, but no development agency is following them except the organizations of disabled people. If we estimate that the number of disabled people is 7 to 10 per cent of the population in developing countries the share of support to disabled people is far behind.

The organizations of disabled people are very seldom taken into consideration either by donor or recipient countries when planning or implementing development cooperation. It is very important that UNDP set an example and start communication with both national and international organizations of disabled people.

Also in Finland communication between the organizations of disabled people and development authorities is insufficient. Over the years there has been positive communication with the NGO-office in FINNIDA but not with the other offices, which plan and implement bilateral and multilateral development cooperation.

There are also serious weaknesses in the philosophy and practice of development coordination from the point of view of disabled people. Even the approaches which are directed to help disabled people – like Community Based Rehabilitation (CBR) – are missing the equal participation of people concerned.

The main areas of development cooperation have prevention and rehabilitation and not the equalization of opportunities which was the third element of the World Program of Action concerning disabled people. The equalization of opportunities is promoted by the organizations of disabled people as a major area for development for the time being.

Prevention is often interpreted as preventing disabilities and not disabling circumstances. Rehabilitation is often interpreted as something which comes from outside and from above trying to change disabled people themselves.

Community based rehabilitation (CBR) and independent living (IL)

In CBR and IL the process starts at grassroots level. Both have strong social ties to community-oriented components. Many articles about both CBR and IL have appeared; here I will refer to the WHO Manual on Training in the community for people with disabilities and a DPI publication “Tools for empowerment”.

The main criticism of CBR is that disabled people do not play the key role. Disabled people are more or less objects. Perhaps this is not so strongly the case as it is in many other approaches, but nevertheless it is a valid point. Through the development of CBR in a direction emphasizing the active involvement of disabled people and their representatives in the planning, implementing, and monitoring process, permanent results could be achieved.

The adaptation of peer counseling and the providing of role models are also very important in CBR. It's potential value has not yet been sufficiently realized in the programs with which I am acquainted with from WHO or ILO reports. In some programs disabled people themselves are involved but it has not been an issue itself.

The biggest mistake in CBR is the lack of respect for disabled people. Empowerment also means the liberation of disabled people in their own right. This should in practice mean that each CBR program should include elements which assist disabled people in organizing themselves.

The problem with IL is that until recently it has only been discussed in developed countries. There are not well developed patterns for independent living in developing countries. This has been recognized by DPI's Independent Living Committee. In the future DPI-ILC plans to hold regional meetings for adapting the global idea to different societies. This can only be done by disabled people in different parts of the world.

Both a specialist and a disabled person himself, Dr. David Werned has spoken about why it is so important that community-based programs be run and are staffed primarily by disabled persons.

“1. Having an impairment themselves, disabled workers tend to be more sensitive to the needs and feelings of other disabled people, and to relate to them more as equals.

2. Because of this sense of equality, disabled workers are more likely to involve those who come for rehabilitation in the problem solving process. This permits disabled persons, even children, to play an important role in evaluating their own needs and in figuring out what therapy or assistive equipment is likely to be effective. thus disabled persons become the subjects, not the objects of rehabilitation.

3. Because of the insight the workers gain from their own disability, the rehabilitation aids and therapy they provide often do better at meeting the real needs – and felt needs – of the user.

4. Most important of all is the role model that disabled leaders and craftpersons present to disabled children and their families. In many parts of the world most parents deeply love their disabled children. But they overprotect them. They do everything for them and don't let them do much for themselves. They may not let them play with other children, or go to school. They expect them to be helpless and dependent. When the parents see disabled villagers in wheelchairs and crutches running the program, providing medical and nursing care, performing a wide range of skilled services, earning their living, raising families, enjoying life and doing more to help other people than most non-disabled persons do, it

gives both the parents and their child a whole new sense of what is possible. And that is the first big step of rehabilitation – or enablement – and ultimately of empowerment.

5. Having disabled persons with limited education as leaders and highly skilled technicians helps to demystify the rehabilitation process in two ways. First, it shows that first hand experience and personal commitment can sometimes outweigh years of rote learning and official diplomas. Second it moves disabled persons – both providers and clients – from the role of passive recipients to active participants in the rehabilitation or enablement process. Thus the example that a competent disabled rehabilitation worker provides not only engenders a new, more open and liberating point of view to the disabled child and family, but also to society as a whole, including non-disabled rehabilitation professionals, whose attitudes are often the hardest to change.

6. Finally, providing hands-on skills training and leadership opportunities to disabled persons in the field of rehabilitation and disability is a valuable qualification rather than a handicap. As we have seen, the experience of disability can also be an outstanding qualification in community health work. I hope the day will soon come where planners and administrators recognize the positive side of disability and – other qualifications being equal – give preference to disabled candidates in job training and leadership roles, especially in relation to work with disabled people.”

Conclusion

In this article I have tried to illustrate some important issues concerning disability and development. Development and development co-operation is not a one-way-street.

Disabled people themselves have a tremendous responsibility for their own development. Without the participation of disabled individuals no fundamental change will take place. This participation places certain demands on the disabled, e.g. problems should be identified at the grassroots level, organizations must be democratic, people have to learn to understand their own societies in order to know how to work there, etc.

At the same time development agencies, governmental, intergovernmental and non-governmental agencies, have the duty and the challenge of supporting and encouraging disabled people in their struggle for equal opportunities and a better life world wide, keeping in mind that the disabled are the poorest of the poor.

To achieve real results, all this must take place in a context of respect toward disabled people, recognizing them as equal partners and full human beings.

Everything is possible, if we work together and by showing greater concern for the disabled we also show greater concern toward people as a whole.