Disabled People's Organisations and Development: Strategies for change

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INTRODUCTION

There is no country in the world where disabled people's rights are not violated. The discrimination, oppression, violence and abuse faced by disabled people does not respect national boundaries, national wealth or national poverty. As a result of our direct experience, and our articulation of our own situation, disabled people have a unique understanding of what constitutes "development" and the social change that is required to ensure our equalisation of opportunities and the enhancement of rights. This unique understanding has shown us that strategic change cannot happen on one front alone. To ensure the empowerment and inclusion of disabled individuals in the development of their own communities and states, strategies for change must be devised to:

- develop, strengthen and resource disabled people's own organisations;
- give disabled people control and choice in their lives and also over the policies and services that directly affect them;
- build a shared understanding that disability is a rights issue and should be defined in the social context;
- ensure that there are significantly improved information networks to raise awareness of the situation of disabled people and of appropriate solutions for change management; and
- recognise and support disabled people as full and equal participants in mainstream activities.

To put all that in simple terms, it is my contention that the development and empowerment of disabled people cannot happen unless the Disability Movement is at the forefront of bringing about social change.

THE DISABILITY MOVEMENT

The Disability Movement is unique among civil rights movements since it is the

only movement which has a democratically-organised international structure as well as structures at national and local levels. Whether it be through the cross-disability national assemblies within Disabled Peoples' International, or through single-impairment organisations such as Inclusion International, the World Federation of the Deaf, the World Blind Union or the World Federation of Psychiatric Users, disabled people at the grass-roots have a mechanism through which they can have a voice, through which they can be understood and supported. Of course, these structures are not perfect and have varying degrees of strength and effectiveness - but at least they are there, to be used as the main instrument through which development takes place.

The history of the Disability Movement worldwide and in the UK has been well-documented (Driedger 1989, Campbell & Oliver 1996), so I focus here on just three points. First, disabled people's own organisations happened as a direct action against the oppression of the medical and rehabilitation professionals and social workers, and their assumption that they 'owned' disability and, by inference, disabled people. Secondly, the movement happened because disabled people with leadership qualities from all over the world had the opportunity to come together and share experiences. And thirdly, disabled people needed to have a united voice to be heard. It was vital that our voice was listened to, that we ceased to be the "silent emergency" as once described by the UN Secretary-General Perez de Cuellar, and became instead the shouting, loud-mouthed demanders of civil rights.

We had this whole plethora of people who were speaking for us, keeping us as children, not allowing us to make decisions for ourselves. There were our families and friends who were shocked and guilty at our presence, and would keep us hidden away or over-protected. There were the medical and rehabilitation professionals who thought that they knew all there was to know about us as individuals because they had some technical knowledge about our impairments. There were the charities set up by righteous individuals to help us, never recognising that they were patronising and disempowering us. And then there were the policy makers, the aid and development agencies and the general public who did their utmost to ignore us, leave us out of their plans and programmes, except when they could find expensive "special" projects for us.

It is vital that our voice is heard at last. Though, because progress is so slow, I often wonder whether our voice really is being heard...whether we are shouting loudly and clearly enough. Whether we are getting our messages across.

LEARNING FROM DISABLED PEOPLE'S ORGANISATIONS

Our understanding of development has moved a long way on from the old saying that "give a man a fishing rod and he will feed himself for life; give him a fish and he will be hungry again tomorrow". That approach to development was an improvement on throwing money at poverty, but it has still not brought about sustainable development or social equity for oppressed and marginalised groups.

It is now increasingly recognised by development professionals and social scientists that the social change necessary to support diverse groups in a society based on rights and equal opportunities will only be brought about by the actions of the groups themselves. So, strengthening the leadership, empowering the grass-roots membership and giving equal status to these social groups and movements is the only effective way to achieve real social development. It is here that the experiences and perspectives of disabled people and their organisations are so important - not just for disabled people...

In 1995, at the World Summit on Social Development, the disability international non-governmental organisations presented a position paper based on their direct experience in empowering and developing themselves through their own organisations: The Disability Dimension, A Joint Statement to the World Summit on Social Development (DPI et al 1995). The main thrust of the paper was that development should start with the people. They said:

> The World Summit on Social Development is an important event which provides an exciting opportunity for a shift in attitudes to and implementation of social policy and development. But changes will only come if new approaches are examined and debated and the people concerned are at the forefront of those approaches and discussions. Development and policy that is not made in full collaboration with the people is never effective. And it is particularly important that disabled people are fully involved in all the World Summit discussions. We have a unique experience and have, over the years, found cost-effective, integrative solutions to our development which are relevant to everyone and should form a basis for the outcome of the World Summit (The Disability Dimension 1995).

The position paper went on to set out solutions and strategies for social change:

In any situation, people find the best solution for themselves. And disabled people have come up with solutions, the solutions of advocacy, independent living, income generation and self-help within our own organisations. All these solutions are based on the principles of integration and equalisation of opportunities and the implementation of our human rights. We know from our own direct experience that it is through these two solutions that disabled people can become participating, contributing members of our own societies. And it is those solutions which should be thoroughly debated and examined by the World Summit.

These solutions are all effective, low-cost and do not require setting-up tiers of professionals to run then. They do not include expensive buildings that have to be maintained and re-furbished. They are the grass-roots solutions that can be applied everywhere - in rural and urban areas - which will benefit everybody and which include everybody. They are solutions that not only apply to all disabled people but to the rapidly growing numbers of elderly people, to children, to the poor, to refugees, to ethnic minorities. They apply to all these groups because disabled people form a part of these groups and it is disabled people themselves, from their experience of extreme deprivation and isolation, who have come up with the solutions.

We have to get this message across. Our solutions work and have been seen to work. If our experience is ignored, then social development will remain what it so often is - politicised charity - and a great opportunity will be lost (The Disability Dimension 1995).

We still have not got these messages across. The barriers of prejudice and ignorance are so strong that those engaged in aid, development and social policy are finding it hard to break them down and to change entrenched ways of behaviour. Although disability did get on to the World Summit agenda and was mentioned in the final Declaration, there was no recognition that our unique experience might underpin broader discussions of social policy and social development. We were still seen as separate. Our voice was not really heard.

DOES DEVELOPMENT EQUAL CHARITY?

Certainly for disabled people, aid and development programmes can remind us quite forcefully of the disability projects of rehabilitation professionals and charitable organisations. Programmes which involve sending workers from a

rich country to poor countries to give money (sometimes in ways that make the rich country even richer), to show what clever things we do in rich countries, and to show the poor how to behave - these are clear parallels with the work of disability charities in the west. Meanwhile, a whole language has been built up around aid and development work which is very similar to the language adopted by social workers when "dealing with" their clients: animation, training, support, care, concern, victims, assimilation, sustainability, marginalised, behaviour patterns. Words like rights, empowerment and participation have only recently begun to be part of the language of development.

As a result, and despite good intentions, development programmes have not achieved what was intended. The numbers of people in poverty remain much the same, health levels are only slowly creeping up in some countries, education is still only available to the relative few, while for the majority, employment means earning just enough money to feed a small family. The gap between rich and poor is widening and in places where there is political upheaval, war or civil strife, the poor do not earn enough to eat. Women remain oppressed, without equal rights, doing two-thirds of the world's work for half the money - if they are lucky. People who have different political or religious views or who do not fit the "norm" suffer constant discrimination. So what is going wrong? And what should we be doing to ensure real sustainable development?

HUMAN RIGHTS AND SOCIAL CHANGE PARTNERSHIP

We must recognise clearly and strategically that real sustainable development cannot take place outside the paradigm of human rights and social change working in partnership. If you develop one without the other, effective change will not result. The ineffectiveness of social change without human rights is demonstrated clearly in many dictatorships.

The inherent ineffectiveness of trying to implement human rights without social change has been less obvious to aid and development agencies. Millions of pounds are spent every year through the British government and non-governmental organisations on grass-roots projects which aim to ensure human rights for a particular group or village. And many of those projects often seem to be very successful and to help the people concerned. However, initial success is no guarantee of sustainable success. Take a project that aims to teach farmers new irrigation techniques to increase crops and improve the local economy. At first, the results are good, but a few years on, some outside political force or natural disaster eradicates those gains and the achievements

are not sustained. Consider what would have happened if, alongside developing new irrigation techniques, the project had sought to empower local people to speak for themselves, to work co-operatively in changing farming techniques, and to join together to ensure that the national government supports the new techniques through appropriate policies. The result: the initial project becomes sustainable through changing the social context and supporting the human rights of the individual. The lesson: development at the grass-roots is not sustainable unless it goes hand-in-hand with social change implemented at the national level.

It is comparatively recent that development strategists have understood that the support of women's self-advocacy, organisation-building and leadership training as well as specific projects on health, income-generation etc. are all essential for sustainable development and the empowerment of women. But so far they have failed to extend and apply that understanding to working with disabled people and their organisations.

THE CHALLENGE TO DEVELOPMENT AND AID AGENCIES

If disability is to be included on the mainstream social development agenda, as it must be if social change and empowerment are to happen, then development and aid agencies will have to revise their approaches accordingly.

Funding and Supporting Disabled People's Organisations

When the disability movement first started, aid and development agencies did support organisations of disabled people. In fact, the concept of organisations of disabled people was so novel that they were clearly seen as a useful development tool and therefore worthy of financial aid. As a result those organisations have grown - in size, experience and effectiveness. They are now running grass-roots projects which not only empower disabled individuals but also widen the membership and enlarge the pool from which potential leaders can be drawn. However, the funding situation has changed and now the only way these organisations can get funding is through running projects - particularly those projects that the funding agencies think are appropriate. Funding for networking, leadership support, or for the straightforward "core costs" of running an organisation is not available. Whilst in those areas where organisations of disabled people have not developed yet, there is no recognition that the only way to promote self-organisation is through networking, leadership training and learning from others.

Funders, it seems, need to feel that they are seen to be directly helping the poor, suffering individual, and directly relieving that poverty and suffering. Spending public money on supporting organisations, whose leaders now seem to be dismissed as the élite, is not considered acceptable. This funding approach is partly driven by market attitudes and the ethos on which charitable giving is based, whereby the haves give to the have-nots directly and on an individual basis. But it is time that funders and development professionals recognised that this ethos does not promote sustainable development. We all have to play our part in getting over the message of human rights and social change partnership, even if this is not an easy message to convey from a "pulls at the heart-strings" - and therefore purse strings - perspective. In the final analysis, what is the point of giving support to a particular grass-roots project if the organisation of disabled people running that project cannot sustain themselves? The project may succeed in the short-term but it is unlikely to succeed in the long-term, and the number of people who benefit will be minimal and unsustainable.

I am not suggesting that funders should not put money into grass-roots practical projects. But I do want to make the point - as clearly and loudly as I can - that only putting money into those projects, and ignoring the need to develop and sustain the self-advocacy rights movement as well, will put the whole development strategy into jeopardy. And as the disability international non-governmental organisations made clear at the World Summit of Social Development in Copenhagen - what works for the Disability Movement also works for all other socially excluded groups.

Disability Equality Training and Development Agencies

Whatever strategies and policies we agree for including disabled people on the development agenda, there will need to be a change of attitude to back up the change of behaviour that such policy and legislation require. It is not enough for an aid or development organisation to have an equal opportunities policy if the individuals in the organisation do not know what such a policy means or how to implement it in practice.

There is an issue about how to get the message of equal opportunities across to aid and development agencies and professionals. Is it appropriate that nondisabled people should be the message-bearers? Should it only be disabled people who give the message? These and other questions have exercised the

minds of many people in relation to training on sexism and racism, and the issues are no less important when it comes to disability equality training. There are also doubts in some people's minds as to the efficacy of equality training. Is it preaching to the converted? Is it possible to change the entrenched attitudes and behaviour of someone in a day or two of training? Probably training only tickles the surface of attitudinal change, but it can be a positive step towards a more inclusive society and social development culture - as long as the trainers fully understand and have direct experience of the issues, know how to convey the messages, and how to help people "own" the message. At the end of the day, there is no doubt that disabled people's own organisations are the essential messengers of disability as a rights issue.

Including Disabled People in All Development Programmes and Planning

One of the most important parts of a sound development strategy must be to ensure that policies are in place which recognise the need to include socially excluded groups in all stages of development work.

Most aid and development agencies have employment equal opportunities policies and many have specific gender policies, aimed at ensuring that gender issues are taken into consideration through all the working and funding practices of the organisation. There may even be a specific percentage of funding for women's programmes. But the number of development agencies who have similar policies for disabled people as employees and as recipients of funding and programmes, can be counted on the digits of a two-toed sloth.

The inclusion and mainstreaming of disability in all social development work is an important strategy. It is also difficult to implement. The habit of excluding us or seeing our programmes as "special" has a long history. Less than a year ago, the head of a major aid agency articulated his firm belief that disability should not be part of his organisation's policy on the basis that disability was a "special issue and had to be dealt with by specialists". Most people are so frightened by anything to do with disability that their reaction to including it on any agenda is inevitably one of rejection. There is also the stereotyped attitude that believes that disabled people are unable to participate in mainstream life. Proponents of this view do not comprehend that we are quite able to participate, but are disabled from participating by others' attitudes and social barriers.

A welcome example has been set by the government of the United States - the only government that has decided to ensure that foreign policy is included in

comprehensive non-discrimination legislation. The new policy will state that a percentage of overall funds should go to disability projects, that disabled people should be included as participants in all other development projects funded by the government, and that all buildings, including embassies, should be accessible to disabled people. In short, and to echo the words of US Secretary of State Madeleine Albright, the United States has decided to implement the Americans with Disabilities Act in its foreign policy (Albright 1997).

In summary, there are disabled people in every section of society, and in every part of the world. To include disabled people and their organisations in all development programmes makes good development sense. To exclude disabled people and their organisations from any development programme is to discriminate against them. Moreover, the strength of their empowerment, their self-advocacy and their accountability to a grass-roots membership can only enhance the learning and experience that disabled people's organisations have to offer. It is therefore crucial that disabled people's organisations should always be involved in planning and policy-making for aid and development work, as well as in setting the parameters for training. This is not a new concept. It has always been assumed that women's groups and ethnic minority groups must be directly involved in setting policy and training agendas that affect them. The same logic and learning must now be applied to disabled people and our organisations by those professionals and agencies who are active in the world of international development work.

CONCLUSION

Development leads to (or should lead to) empowerment - of a nation, of a group, of an individual. Empowerment cannot happen without the full involvement of the nation, the group and the individual. A nation will not be fully empowered unless its citizens are empowered. A group will not be empowered unless their peers are empowered. Nor can an individual's empowerment take place in isolation from others. Moreover, empowerment cannot and will not happen without social change. Social change can create the circumstances that allow empowerment. Empowerment can also create the circumstances that allow genuine social change and sustainable development.

The history and comprehensive nature of disabled people's exclusion in society is such that radical and far-reaching social change is necessary if empowerment is ever to be real for disabled people. The empowerment of disabled people which follows will then produce another social change: the creation of a society

which recognises the unique contribution that can be made by disabled people. It is a contribution that no "developed" society or world should be without.

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