Programmes and Partnerships

Emma Stone

Disabled people's organisations are usually much smaller and less resourced than other key players in the disability and development field. There are the United Nations agencies like the World Health Organization, International Labour Organization, UNICEF (child focus) and UNESCO (education, science and culture focus). There are governmental development agencies like DfID (Department for International Development, Britain) or SIDA (Swedish International Development Agency). There are major international and national non-governmental organisations (NGOs) with a global development focus like Save the Children and Oxfam. There are international and national organisations with a disability-related focus - most of which are not controlled by or democratically accountable to disabled people at the grassroots (e.g. Rehabilitation International, Leonard Cheshire Foundation International, SENSE). And that is not to mention the host of smaller organisations that are involved in development and/or disability worldwide.

The impact of disabled people as activists, as professionals, and through their own organisations on these other key players has varied widely - not just between but also within different organisations. At best, development professionals are forming real partnerships with disabled people's organisations, supporting them to undertake the work they have identified as important. At worst, development professionals continue to function in "charity mode" or "expert mode" or "rescuer mode".

Working with disabled people at the grassroots, and working in the field of disability and development generally, is not straightforward ... especially when you want to work in ways that fit (more or less) with a social model standpoint. In this section of the book, you will learn something of the experiences that development and disability professionals have faced in trying to do just that.

OVERVIEW OF CONTRIBUTIONS

ADD: Working with Disabled People's Organisations in Developing Countries
Barbara Frost sets out the vision, aims and objectives of Action on Disability and Development (ADD), why it was set up, and its modes of operation. ADD works exclusively with and through disabled people's organisations in the

majority world, to promote change and human rights. Frost also outlines some of the difficulties that ADD has faced in its 12 years as a development organisation focused on disability - including difficulties relating to: which disabled people to work with; and how to work in ways that give more power to local people, when it's the western organisation that has access to the resources.

Integrating a Disability Perspective into Mainstream Development Programmes: The Experience of Save the Children (UK) in East Asia

Hazel Jones tackles the difficult issue of whether it is better to set up development projects that have a specific disability focus, or to integrate a disability perspective into all mainstream development projects. The issue is illustrated using examples (good and not so good) from Save the Children's work in Lao, China and Viet Nam. Jones also offers a "Framework for Integrating a Disability Perspective" with some practical suggestions on how to implement this.

Creating Conversations: The Evolution of the Enabling Education Network

Susie Miles writes about the Enabling Education Network. EENET promotes international networking and information exchange to support the inclusion of all marginalised groups in education. Miles outlines EENET's aims, ways of working, and some of the difficulties encountered so far. Along the way, Miles considers: the concept of inclusion (versus integration); issues of global power imbalances in information production, control and access; and the need for professionals in the minority (western) world to listen to and learn from initiatives that are happening in the majority world.

Challenges for Universities of the North Interested in Community Based Rehabilitation

Sheila Wirz and Sally Hartley draw on their experiences in research, training and practice at the Centre for International Child Health in London to inform their discussion of the role that universities of the minority world might play in disability research and service provision in the majority world - through training, partnerships, research links, etc. Wirz and Hartley also consider the transfer of western approaches and professions to other countries; the dangers of "professional fashions"; and the potential mutual benefits of North-South partnerships.

DISCUSSION POINTS

- Should all development organisations take disability issues on board? If so, how?
- Is it better to include disability issues and disabled people in all development projects, always? When, if ever, is it better to have a project that is only focused on disabled children or disabled adults?
- What are the benefits of working, as ADD does, with organisations led and controlled by disabled people in the majority world? Are there any dangers?
- What practical steps can be taken to support the development of disabled people's organisations worldwide, at local as well as national levels?
- Do you think students and practitioners from the minority world have anything to learn from research and practice in the majority world? If so, what? Would western practitioners really listen to people from the majority world?
- What do you think about the transfer of ideas and ideologies like "inclusive education" to majority world settings?
- Should westerners and western-dominated organisations be involved in disability issues in the majority world at all? Why, or why not?

Action on Disability and Development: Working with disabled people's organisations in developing countries

Barbara Frost

(Chapter 4 in Stone, E. (ed.) 1999: Disability and Development: Learning from action and research on disability in the majority world, Leeds: The Disability Press pp. 21–24).

INTRODUCTION

Action on Disability and Development (ADD) is a UK-based non-governmental development organisation, working in Africa and Asia to promote the equal opportunities of disabled people (especially disabled people in poverty) and the development of the disabled people's movement. ADD believes that disabled people should be included in all aspects of overseas development work, and that the issue of disability should be a cross-cutting theme, as gender has become in recent years. ADD is a relatively small agency with 68 staff worldwide. In 1997, ADD had an income of £1.6m.

The paper explains why ADD was established. It goes on to describe ADD's vision, aims, operational objectives, ways of working. I also outline some of the key issues and dilemmas which we have encountered within our organisation and in our operations overseas over the past 12 years. Issues related to governance, resource management and fund-raising are not included here, but are covered in ADD's Five Year Strategic Plan (ADD 1998).

ADD: THE BACKGROUND

ADD was set up in 1985 by Chris Underhill, who had been inspired by the work of the disability movement in Zimbabwe, where organised self-advocacy by disabled people's organisations was having an impact on attitudes and policy.

During the mid-1980s, other international non-governmental development agencies had identified disabled people as being among the poorest people in the majority world. However, disabled people's needs were all too often viewed from a medical perspective, related only to their impairment. As a result, interventions by development agencies generally took the form of specialist services, provided by medical professionals, and with little involvement by

disabled people themselves. In short, the services and approach were premised on a view of disabled people as "different", with very "different" needs from the rest of the population. In fact, the priorities for most poor disabled people were no different from the priorities of their non-disabled neighbours: food, clean water, shelter, health care, schooling for their children, and the means to make a livelihood.

Many non-governmental organisations (NGOs) claimed to be doing "integrated" development work: by this, NGOs meant a focus on the holistic needs of poor people. However, the vast majority of these NGOs had not even started to consider a fully inclusive approach to working with and supporting all poor people. Gender issues were beginning to be raised, but still disabled people (men, women and children) were generally excluded from grass-roots development programmes.

Clearly there was a need for an organisation which would target poor disabled people and help build the capacity of disabled people's organisations to push forward their demands for equal opportunities and socio-economic inclusion. It was with this in mind that ADD was established in 1985, as a development agency working with disabled people's organisations in developing countries, and with a specific development focus on issues of poverty and exclusion.

ADD positioned itself alongside other international aid and development agencies working towards the reduction of poverty through self-help initiatives, and was also keen to align itself with the growing international disability movement (e.g. Disabled Peoples' International). ADD was not established as an organisation controlled by disabled people, although it has established an affirmative action policy in choosing staff and trustees (at least 50% should be disabled people), on the basis that a personal understanding of the negative attitudes, oppression and discrimination experienced by disabled people themselves is vital to the organisation if it is to work effectively.

ADD remains the only British-based development agency supporting development work exclusively with groups and organisations of disabled people in Africa and Asia.

VISION AND AIMS

ADD's vision is a world where all disabled people are able to participate fully at every level of society. We believe that all people have the same fundamental

rights to determine their own futures and to control decisions that affect their lives.

ADD aims to promote the human rights agenda of disabled people in the developing world and believe that disabled people are their own most powerful advocates. More specifically, our aim is to work in partnership with groups of disabled people in some of the poorest communities in the world to support their campaign for the rightful inclusion of disabled adults and children in society. We aim to achieve this by promoting disabled people's organisations to work with their members and other disabled people (to build the confidence of local disabled people in their own worth, abilities and rights); to set up self-help initiatives to improve their own standards of living; and to take control of their own lives.

OPERATIONAL OBJECTIVES

There are six main operational objectives which are reflected in the rolling five year plans and activities of all ADD's programmes and partners, all of which are achieved through supporting the activities of disabled people's organisations (ADD 1998):

1. Building Strong Associations of Disabled People

- To work with disabled people's organisations (DPOs) to develop democratic effective organisations with plans which will allow them to raise the social status of their members and to lobby effectively for equal opportunities.
- To assist DPOs to link up with, or join, existing movements of disabled people.
- To support DPOs who are tackling issues of attitude, power and control in an endeavour to challenge the causes of their oppression.
- To assist disabled women and children to organise themselves and pursue initiatives to improve the quality of their lives.
- To develop partnerships with groups of disabled people who are most marginalised within their societies e.g. people with mental illnesses, learning difficulties or hearing impairments and look at innovative ways of working with them.

2. Self-Advocacy and Influence

- To assist disabled people to advocate effectively at national level for laws which guarantee disabled people's rights and compliance with the UN Standard Rules.
- To work at district and regional levels with disabled people's organisations in lobbying for equal opportunities.
- To influence policy makers, development agencies and NGOs to adopt an inclusive approach to working with disabled people.
- To assist disabled adults and children to be involved in decision making about activities designed to benefit them e.g. HIV/AIDS messages, community based rehabilitation, mobility aids, health, transport and educational services.

3. Access

- To ensure that local institutions and services e.g. transport services or schools are accessible.
- To support organisations which are providing appropriate mobility appliances or aids to disabled people.

4. Economic empowerment

- To provide information and training to disabled people in managing their resources effectively.
- To lobby local financial service providers to include disabled people.
- To assist disabled people to gain access to vocational training.
- To provide training for disabled people in setting up their own small businesses, and provide start up capital for revolving funds.

5. Information and Education

- To ensure that development messages and information are accessible to disabled people, e.g. AIDS messages in Braille or sign language, to overcome any sensory or physical barrier to communication.
- To provide information on, for example, mobility aids, good health, HIV/AIDS, entitlements to schooling or other state services.
- To help disabled people and their communities to become aware of the causes of different impairments and encourage parents, for example, to

have their children immunised against polio.
- To support literacy and numeracy work.
- To encourage Governments and schools to take on an inclusive approach to education by adopting suitable curricula and training for teachers.

6. Recreation, Sport and Cultural Activities

- To support recreational, sporting and cultural activities chosen by disabled people.
- To encourage drama, dance etc. to raise awareness, disseminate information and provide a basis for disability culture (ADD 1998).

WHAT WE DO & WHAT WE DON'T DO

The way in which ADD carries out its operational objectives is crucial. In our ways of working, we adopt the social model of disability, whereby the onus is on society to change and become more inclusive of diversity, including disabled people.

Solidarity with Disabled People

ADD works through establishing partnerships with disabled people's organisations either through country programmes or directly from the UK. We work with organisations or groups who share our aims, values and beliefs and who have been established along democratic lines to seek equal opportunities for all disabled people. ADD also partners groups who work towards the inclusion of disabled children in society and education. We believe that disabled children's rights are often advocated most effectively by parents and carers organisations.

In terms of best practice, we feel that solidarity with disabled people is crucial. If development initiatives concerning disabled people are not in solidarity with them, there is little sense of ownership and the project collapses as soon as funding ends. Initiatives which are planned, carried out, managed and evaluated by disabled people themselves are likely to be more sustainable in the long-term.

Partnership Agreements

We believe in the concept of "partnership", while acknowledging that this can

only occur when a level of trust is built. To help build this trust, ADD sets up agreements with partner organisations, which state clearly mutual expectations, obligations and duration of support.

Support for Self-Help

ADD believes in backing self-help initiatives which have been planned by disabled people themselves. ADD supports a community development approach with disabled people's groups identifying and tackling the causes of their poverty and oppression. In this way, development is part and parcel of an on-going process of self-empowerment and liberation. This approach respects the rights of disabled people to determine their own futures.

Support for Capacity Building

Much of our work focuses on building the capacity of organisations through training and support in organisational development. This may take the form of "direct" capacity-building - such as building the management capacity and skills in a disabled people's organisation; or it may be "indirect" - such as supporting disabled people's organisations to achieve their operational objectives.

ADD tries to be responsive to the plans and priorities of the various organisations it works with. Often it is appropriate to maintain support to initiatives and organisations operating at different levels within a country. For instance, in supporting a National Federation of Disabled People, the priority might be an understanding of effective advocacy and lobbying techniques. For a village-level group, the priority might be gaining access to livelihoods and income-generating opportunities. At regional and district level, ADD's support might be geared towards membership development programmes or local awareness raising.

What We Don't Do: Relief Work and Rehabilitation

ADD does not get directly involved in emergency or relief work, although we recognise that such disasters often increase the numbers of disabled people in any community. However, we do accept a responsibility to influence aid and development agencies which provide emergency relief: those agencies must plan for the needs of disabled people, who are often severely disadvantaged and tend to be excluded from mainstream aid and relief work.

In relation to rehabilitation, including community-based rehabilitation (CER), ADD sees its role as complementing the work of CBR programmes and relevant agencies and, crucially, influencing them to take on the social model of disability. In some countries, we do support disabled people's organisations who produce low-cost appropriate prosthetic appliances and train disabled men and women as technicians.

ORGANISATIONAL CULTURE & EQUAL OPPORTUNITIES

ADD believes that in order to establish effective relationships with our programme staff and partner organisations, we need to make our values, beliefs and ways of working explicit and consistent with our approach to community development. We also want to build an organisation which is constantly learning, reflecting and improving practice; and which reflects the values which inspire and drive our work:

> We aim for a culture which is decentralised, trusting, empowering, informal, and flexible. While accountability must be paramount, we will aim for an ethos which emphasises freedom, initiative and humour (ADD 1998).

ADD has an Equal Opportunities policy which aims to ensure we recruit the best person for the job while guarding against inappropriate discrimination. We have an affirmative action policy with regard to the appointment of disabled people: wherever possible, disabled people are recruited. Accessible premises, suitable equipment and fittings, part-time positions and flexible working hours are provided to facilitate this.

WHERE ADD WORKS

ADD has six well-established and staffed programmes in Africa. These are located in Uganda, Sudan, Tanzania, Zambia, Ghana and the "West Africa" programme which covers Burkina Faso, Mali and Côte d'Ivoire. In Asia, there are two staffed programmes in Cambodia and Bangladesh. In addition to staffed programmes, ADD provides support to partner organisations in Zimbabwe, South Africa and India, including to a sister organisation, ADD India, which has an independently constituted board.

KEY ISSUES & DILEMMAS

In this final section of the paper, I set out some of the key issues and dilemmas that ADD has faced in its work in Africa and Asia. These relate to: partnerships; influence and self-advocacy; gender issues; HIV/AIDS issues; financial services and income generating projects; learning and evaluation. ADD does not have all the solutions to these problems, but believes that it is important to reflect on the weaknesses - as well as the strengths - of our work.

Partnerships

Partnerships are much easier said than done. In ADD's work, we have come up against several difficult issues and questions. These questions are discussed in turn.

- Does ADD only work with cross-impairment groups?

As a general rule, ADD does not work with single impairment groups concerned with service provision. In some countries, however, only impairment-specific organisations exist. In these circumstances, ADD may support such organisations whilst encouraging the formation of a single disability organisation. One of the reasons why we prefer to work with cross-impairment organisations is that, from our experience, governments and policy makers are more likely to listen to a single unified voice representing the interests of all disabled people.

- How representative are the disabled people's organisations that ADD supports?

ADD tries to support groups that are genuinely democratic, involve women as well as men, and involve a cross-section of disabled people in their work. However, as with all organisations, disabled people's organisations may be dominated by the most powerful individuals within the disability movement, while the more marginalised may not gain a voice. Leaders are often physically disabled men which, given the young age of the disability movement in most countries, is not surprising. People with learning difficulties, leprosy, epilepsy or mental illness rarely gain equal access to these cross-impairment groups (largely because their impairments are surrounded by more myths and misconceptions than those of other disabled people).

The marginalisation of disabled women is another major concern. ADD encourages discussion of gender issues and women's participation and exploitation. That said, ADD also acknowledges that challenging gender dynamics has to come from within the society and culture. ADD's dilemma is how to promote discussion on gender issues and increased representation of disabled women without imposing western views. As much as we may seek to promote better representation of women, it is disabled women themselves who must lead this struggle. And disabled women are doing precisely that. In Sudan, I recently heard a young deaf women declare to another friend: "What good will a husband be? It is skills and an income that we need".

- What happens when disabled people's organisations compete?

Again, as with all community-based groups, power struggles and breakdowns between elected boards and staff occur, and ADD has to be careful about how to deal with these dynamics. In some countries we have made a deliberate decision to concentrate our work in rural towns where there are fewer disabled people's organisations, rather than in the capital city where political rivalry between the more and less established organisations may make it very difficult to decide who to support.

- How equal can any partnership with ADD really be?

As stated in an earlier section, ADD recognises that partnership requires trust - therefore partnership agreements are used. However, given the colonial history of many of the countries in which we work, building trust takes time and understanding. Moreover, any partnership with ADD is inevitably based on an unequal distribution of resources: ADD accesses the funds, and therefore ADD holds power. Whatever we strive to do in creating partnerships, we must also recognise the inherent inequalities.

- Doesn't ADD's accountability to other donors compromise ADD's partnerships?

Since ADD is almost entirely dependent on project grants to finance its work, we are therefore subjected to rigorous accountability and monitoring requirements by our donors. These requirements are consistent with operating an effective NGO, but they also lead to conflict when (as has happened) increasing amounts of time are spent on improving documentation, planning and monitoring, with less and less time spent actually carrying out the work and working directly with

disabled people's organisations. This works against the development of partnerships when it appears that we are making heavy demands on a group and, perhaps, not fulfilling our obligations.

A Local Presence?

In our experience, the absence of a local or country presence makes it harder to work closely with disabled people's organisations to help in their organisational strengthening and development. Therefore, in most countries in which we work a small country programme office has been established (an office and a small team of development and support workers with a programme manager overseeing the work). The drawback to a local presence is the danger that in building an ADD structure (by setting up a country programme office), the local ADD office will come to be seen as the power base, rather than the disabled people's organisations. There are also difficulties relating to employing disabled people to work for ADD in the country programme offices. Disabled people may leave their own advocacy organisations to join the ADD team, as the pay and conditions are comparable to other NGOs and therefore better than most local organisations can afford to offer.

In countries where no office is established, ADD's ability to work closely with disabled people's organisations in capacity-building is more limited. Our role is likely to become one of a funding agent that relies heavily on other local agencies to provide training and support. Certainly, this can be a workable model for supporting disabled people's organisations that are more established and that therefore require little more than financial support from ADD. However, since ADD also aims to support less established, more marginalised disabled people's organisations, this way of working can have severe limitations. ADD has to continually redefine its role as an agency working to strengthen the capacity of all levels of the disability movement, supporting smaller, more isolated groups to link into the wider movement, and also building lobbying skills at central level.

Influence and Self-Advocacy

ADD is not an organisation of disabled people and therefore is not in a position to advocate directly for disabled people. Self-advocacy skills are critical for disabled people's organisations if they are to achieve lasting social change.

In developing ADD's strategic plan, a "visioning" exercise was carried out with

all stakeholders (disabled people's organisations, country programme staff, UK-based staff and trustees). All felt it was important for ADD to take a proactive role in influencing policy makers to adopt an inclusive approach to their work. We believe that our credibility to do this relies on constantly building on our accumulated experience in working with disabled people's organisations.

In addition to supporting local and national disabled people's organisations in developing countries to lobby power-holders and policy-makers in their own country, ADD has been in dialogue with the Department for International Development (DfID) in Britain regarding the revision of their technical note on disability as applied to NGOs working with disabled people. We have called for a complete revision of this to reflect the social model of disability. We have also called on the British government to establish a policy of including disabled people in all bilateral-funded aid programmes as well as NGO activities. ADD has also tried to facilitate the inclusion of disabled people's organisations on World Bank consultative committees which involve development organisations from the South.

ADD takes every opportunity to ask development agencies and development professionals how they are including disabled people in their work: we are continually amazed at the low-level of awareness, and the absence of a disability equality perspective. Taking account of gender issues is now a requirement of several funding, aid and development agencies (including DfID); we would like to see disability and access requirements treated in the same way.

HIV/AIDS Issues

ADD is aware that malaria still kills far more children in Africa than die from illnesses related to HIV/AIDS. Yet the impact of HIV/AIDS on the countries where we work is something that we cannot underestimate. It is clear that ADD must take a position on this, since very few of our present programme plans include support to activities related to HIV/AIDS.

There are issues regarding disabled people's access to health messages. Also, disabled women may constitute a particularly high-risk group. We have encountered many disabled women who want to find a husband and have children. However, there may be strong social prejudices which prevent them from marrying. Sometimes the wish and pressures to have children may outweigh the risks of contracting HIV/AIDS. Also, women who are seen as less

marriageable may also be seen as less likely to be HIV positive, and thus become more likely to be sexually abused.

ADD has a duty to raise awareness and provide support to our own staff on HIV/AIDS. We also have a role in supporting disabled people's organisations to assess their own position regarding HIV/AIDs and to provide contacts with NGOs and service providers active in HIV/AIDS-related work.

In Peter Coleridge's book Disability, Development and Liberation (1993), he likens the liberation struggle of disabled people to that of other civil liberty movements. The struggle against stigma, prejudice and exclusion which people with HIV/AIDS face is another liberation struggle which many have yet to join. There would appear to be many experiences that the growing disability movement and the embryonic movement of groups of people with HIV/AIDS could share.

Financial Services and Income Generating Projects

Overcoming poverty is clearly a priority for most of the disabled people ADD works with and we want to support disabled people in their endeavours to improve their standard of living. Disabled people face additional obstacles in establishing income generating activities due to lack of education, mobility constraints and limited access to credit through the normal channels. Building the capacity of disabled people's organisations to deal with credit and to establish sustainable income generating projects requires specialist skills, so wherever possible ADD tries to work in partnership with other NGOs who specialise in this.

Where ADD is directly supporting credit work a grant is normally made to the disabled people's organisation, which then disseminates this as repayable loans to create a revolving fund. Before credit is given out it is important that the recipients understand the expectations and repayment requirements. If it is to be used for income generation, then training is provided in conducting a feasibility study and formulating a basic business plan.

There is a danger that if local organisations see ADD as a credit fund provider, the operation of a credit scheme will become the main aim of the disabled people's organisation, instead of the organisational development work which ADD considers most important (from the perspective of building strong local organisations capable of promoting opportunities for all local disabled people).

An additional dilemma relates to donors, and the types of credit schemes that they find acceptable. Most donors want to support sustainable revolving loan schemes. This often puts credit beyond the reach of some of the poorest individuals and households. ADD's experience is that credit management can assist disabled people to gain the respect of their communities. To paraphrase Jim Wolfensohn (head of the World Bank), the key issue is less about "being credit worthy", and more about "engaging in society". The opportunity to "engage" is exactly what disabled people are seeking to achieve. The demonstration of disabled people receiving small-scale credit can achieve much in terms of attitudinal change.

It is often assumed that anyone can run a small income-generating activity if capital and training are provided. We know from the high failure rates of small enterprises the world over that this is unlikely to be true. Therefore we are currently reviewing ADD's experience and lessons learned.

Learning and Impact Assessment

Our aim is to consolidate our learning and document this for internal and external use. However, this requires time and resources which - for a small agency dependent on project grants - is not always easy to do without letting operational activities slip, and without letting "indicators, targets and evaluation processes become the newspeak of the age, often substituting for the facts of power relations, exploitation and poverty" (Zadek 1996).

We want to encourage partners and programme staff to exchange information and create learning groups, and have planned to hold a meeting of all our Programme Managers in Uganda to launch this process. Improved impact assessment will also feed into this process, so that we can plan what to do with a better understanding of current impact and value for money. Social impact is not a short-term goal and meaningful indicators have to be developed with local organisations, at the outset. It is important to build a learning organisation which reflects on its experiences, shares the lessons learned, whilst not sinking under a pile of bureaucracy and paperwork.

CONCLUSION

In the recent Government White Paper on Eliminating World Poverty: A Challenge for the 21st Century (1997), the importance of "encouraging

democratic structures which can hold government accountable and give the poor a voice" was highlighted. ADD views the development of the disabled people's movement as an example of such a structure - and one which has had notable success in influencing policy. For example, the National Disabled People's Union in Uganda has successfully lobbied the Ugandan government to bring about constitutional change with six disabled people being voted into parliament. In South Africa, as a result of links between the African National Congress and the disabled people's movement, a legislative environment has been created which requires that disabled people must be treated equally and affirmative action policies have been implemented. (Here, it is interesting to note that the legal protection for disabled people in a number of African countries is far ahead of anything achieved so far in the UK.) Supporting and working in partnership with disabled people's groups and organisations, at all levels and worldwide, is crucial for change.

Until fundamental legislative changes are realised disabled people are unlikely to realise equal opportunities. Until all development and aid agencies (governmental and non-governmental) make their programmes fully inclusive of and accessible to disabled people, development work will continue to marginalise. Taking account of gender as a cross-cutting theme is now a requirement of many aid and development agencies (including DfID); we would like to see disability issues treated in the same way.

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