

ADVOCACY LESSONS FROM THE DISABILITY MOVEMENT: EXPERIENCES FROM SOUTHERN AND EASTERN AFRICA

Jabu Manombe-Ncube

In this paper I briefly:

- explain the work of my organization, Development Initiatives and Services (DIS);
- explain the historical background to the origins of the disability movement on the African continent;
- describe some of the important issues the movement is dealing with, and outline some of the challenges it faces in its effort to carry out effective advocacy; and,
- share some advocacy experiences from working with organizations of disabled people in Southern and Eastern Africa.

As a conclusion, I highlight some of the challenges from case studies that show a need for continued advocacy.

Development Initiatives and Services

DIS was formed in 1990, and began operations in March 1993. It is a not-for-profit development agency that provides consultancy services to organizations of disabled people in Eastern, Central, and Southern Africa in areas such as organization development and capacity building, evaluation, planning, and fundraising.

Its trustees, who number seven, are drawn from countries within the regions in which it operates. Its consultants are drawn from the regions in which the organization is active.

As the five-year strategic plan of the organization states, the organization's uniqueness derives from its commitment to innovation in the area of disability and development. Because it is a mobile service, it is constantly in touch with a variety of organizations which it supports. It is well placed to identify emerging issues of common interest among disability organizations. It often arranges "think tank" sessions on some of these emerging issues, some examples of which include:

- the issue of political representation of disabled people in national governance structures (January 1996, Mbarara, Uganda);
- the participation and involvement of women with disability in the existing organizations of disabled people (September 1998, Harare, Zimbabwe);
- the relationship between disability and aging (March 2001 workshop, Nairobi, Kenya).

Being a professional agency, DIS sees its role as that of supporting the building of a viable disability movement in the African continent through the provision of inputs which people's organizations themselves identify and thus invite DIS to provide.

The fact that it is a service run by disabled people, without being controlled by the disability movement, means DIS can offer independent advice which is well informed by the experience of its consultants and advisors who have emerged from their practice in the disability movement and mainstream social development sectors. As a result, they have earned considerable respect from the disability movement, and have been used as mediators on occasion in certain conflict situations arising within and between organizations.

Factors that Influenced the Emergence of the African Disability Movement

The establishment of Disabled Peoples International (DPI) in Winnipeg in 1980, involving representatives of organizations of disabled people from both the developing and developed world, marked a major milestone in the development of the global disability movement, and of regional and sub-regional movements in particular. At no other time did professionals in the field and philanthropists face such a major challenge to their dominance in the disability field by the disabled people themselves. This indeed marked a paradigm shift from service provision by philanthropists, to the articulation of disability as a human rights and development issue, and the demand for equal participation and inclusion of disabled people in all issues concerning them.

The declaration of 1981 as the International Year of Disabled Persons by the United Nations brought visibility and some considerable resources to the disability agenda. The International Year was followed by the UN Decade (1983-1992) on the World Program of Action Concerning Disabled Persons, which served to bring further visibility of disability issues at the UN and other levels across the globe.

The past two decades also saw the final stages of popular struggles against authoritarian and colonialist regimes in countries such as Zimbabwe, Namibia, South Africa, and Uganda. These struggles influenced demands for political and economic change (Camay and Gordon, 1998). The conditions also influenced the emergence of the disability movement, alongside the wider general demand for democracy and the inclusion of marginalized people in the building of new democracies.

Issues and Challenges of Building Capacity for Effective Advocacy Within the Disability Movement

Building Viable People's Organizations

It is not enough to discuss the subject of advocacy without analyzing and understanding the crucial role that people's organizations must play in its execution. If advocacy is to be sustainable and is to be employed as a tool for social empowerment and development, then we begin to appreciate that it has to be grounded in the commitment and skills of the people through their own organizations. Building people's organizations becomes a crucial building block for working towards democracy through enabling people's own organizations to achieve a capacity to undertake advocacy at different levels in order to secure different objectives.

Disabled people's organizations do not exist to create exclusive islands away from general society, rather they represent the means through which disabled people organize as part of civil society to achieve broader influence within general society, the public and private sectors.

Thus, one of their key roles relates to their function in innovating and constantly finding new ways of working and broadening their influence. Some organizations in countries such as South Africa and Uganda have been exemplary through their achievements in the representation of disabled people at different levels of governance, in influencing policy development, and legislation. One of the most common weaknesses in African countries is the absence of policies and resources that seek to promote the position of disabled people, and people's organizations have an important role in working to change this situation.

In doing so, they need to enlist the support of allies among development organizations, government, and business towards the disability agenda. These need to be educated about the issues involved and their awareness raised so that disability issues become their own also.

Addressing Gender Issues in Disability Organizations

Democracy cannot be built by excluding some sections of society, including people with disability, the poorest of the poor, those who suffer from different forms of violence, and tribal minorities (so-called). Women in all of these categories are doubly disadvantaged because of the low status they are given in male dominated societies.

By avoiding gender issues, we cannot build viable people's organizations, let alone a democratic culture. My argument is that advocacy as a tool for social change must not be understood only as a need to target external forces, but needs to start within our very organizations. The practice and skills to do effective and successful advocacy need to be honed from within by fighting internal gender injustices within our own organizations and campaigning to change them.

Understanding the Relationship Between Disability, Poverty, and Education

Disability and poverty belong together. Poverty often leads to disability. It is likely that disabled people are disproportionately more among the poorest of the poor. However, there is a need for the disability movement to establish empirical evidence to support this assertion, as opposed to reliance on anecdotal testimony.

Understanding the relationship between disability and poverty will help put into perspective the challenge of building a movement on the back of its poor mass membership who have had little access to education and training. This will further deepen understanding of the challenge of building a capacity in the disability movement for effective advocacy given the objective reality and inherent difficulties involved.

Understanding the Relationship Between Aging and Disability

Here, I am arguing that it is necessary for the movement to be "at peace" with itself in terms of its ability to be inclusive of all elements that comprise its constituency, if its advocacy is to reflect the variety of that constituency's needs.

The extent to which the wisdom of the older members who have lived with disability is being tapped and their own specific needs are being addressed, seems to be important not only in building towards democracy, but also in designing advocacy programs that are relevant to people's needs.

Understanding Disability as a Human Rights and Not a Charity or Welfare Issue

The social model views disability as a social construct, and not a personal disaster for the individual concerned. It is the interface between an individual who has a special need as a result of the limitations that impairment may impose, and the environment that has been designed for and by so-called normal society that needs to be critically examined. Evidence abounds of thoughtless construction of the physical environment that takes no account of the special needs of some sections of society.

The medical model situates disability as a problem at the individual level, requiring that the individual be "rehabilitated" to bring them back into the normal society. It is like molding a person to make them look like the rest of us! The able bodied society is viewed as the "normal" standard to which all must submit. Rarely is the appropriateness of this standard questioned in terms of the underlying attitudes it demonstrates; nor is the need for the standard itself to be rehabilitated ever considered.

This distinction is necessary to understand if the movement is to design advocacy strategies that are in line with its philosophy, and which are based on issues that reflect this philosophy.

Confirming the Philosophical Foundations and Basis of the Disability Movement

Based on the above, it will therefore be understood that the movement is underpinned by an ethos that asserts that disabled people are part of society, and have a right to be proud of who they are, even if they do have different needs. Advocacy strategies that arise from such an ethos need to reflect this philosophy.

Leadership

A discussion of people's organizations cannot be comprehensive without understanding the crucial role that leadership plays in building effective organizations, or failing to do so. My experience in the disability movement reveals that leaders don't only emerge in response to new challenges. They need to be deliberately groomed and developed so they may see emerging trends and challenges in the operating environment, and position the organization appropriately to respond and take control of those challenges.

For advocacy this means that the choice of issues and the execution of strategies to move them forward are matters which require careful management by a leadership that is aware of the inherent risks and opportunities. Furthermore, the leadership needs to understand how such advocacy shapes the overall future performance of the organization. Put differently, the question is whether past and current advocacy work has contributed to improving the organization's overall performance, or an aspect of its programming? This suggests a leadership which

understands that advocacy, and indeed the very organizations which carry it out, cannot be an end in themselves, but are a means to certain ends.

Advocacy Experiences from Organizations of Disabled People in Southern and Eastern Africa

Zimbabwe

In the effort to secure a policy environment conducive to the promotion of disability issues, the disability movement in Zimbabwe through its umbrella organization submitted draft legislation to government in 1990 for its consideration. This draft aimed to promote the rights of disabled people, prevent “wanton discrimination against people on the basis of disability,” (Camay and Gordon, 1998: 75) and improve services for disabled people. This followed several years of efforts to create increased awareness of disability issues in key sectors of government through meetings, lobbying and other awareness raising methods.

The draft was not accepted by the government. Instead, the government went on to draft its own version which sought to emphasize the institutionalization of disabled people. This was strongly resisted by the movement. Subsequently, the Disabled Persons Act of 1992 was passed. It did not represent all that was considered key by the movement, but did include some of the sought after protection that had been included in their first draft.

The movement has sought to establish legal precedents through court rulings in favor of disabled persons. So far this has not been achieved, as some of the defendants have been quick to seek out of court settlements.

A major exercise was undertaken following the passage of the Act to have it discussed and analyzed by the structures of the disability movement in an effort to increase awareness of its provisions, and to reveal some of its shortcomings. One of the weaknesses identified was the lack of government commitment as reflected in the continued absence of resources to ensure the Act's implementation.

In early 2001, DIS and the Southern Africa Federation of the Disabled (SAFOD) initiated a process which brought together 10 organizations of disabled people to discuss the unity of the movement, and its response to the deepening onslaught on democratic values in the country by the governing party. The likelihood of an attack on the disability movement could not be ruled out in the prevailing circumstances.

The participating organizations have agreed on a follow-up strategy to the meeting. Both Canadian CIDA and Swedish SIDA have indicated strong support for the process which aims to strengthen the unity of the disability movement so that it can be better placed to campaign for disabled people.

Uganda

On the African continent, Uganda provides a very good example of what can be achieved by the disability movement, given good leadership who can seize opportunities when they arise, and a political environment which is conducive to change.

When the process to develop a new constitution for Uganda started in 1992/3 disabled people, through the National Union of Disabled People of Uganda (NUDIPU), submitted proposals to the Constitutional Commission. When the Constituent Assembly was set up to create a new constitution based on the draft that had been developed by the Constitutional Commission, disabled people lobbied successfully for one of their members to be included alongside other marginalized groups such as women and youth. This initial success set in motion an historical train of events previously without known precedent in the African region.

It was the late Eliphaz Mazima, a NUDIPU representative, who worked closely with other members of the Constituent Assembly to influence the passage of clauses that were to change the face of disability politics in the country. The disability-friendly provisions enacted by Parliament to date were presented to a National Conference for District Union leaders and councillors representing people with disability in July 2001:

The basic legal framework for enacting laws favorable to people with disability (in Uganda) start with the provisions of the Uganda Constitution 1995. The Constitution addresses the issues of people with disability in the following ways:

- | | |
|------------------|---|
| Objective (vi) | Emphasizes gender balance plus fair representation of marginalized people |
| Objective (xvi) | Calls on society to recognize the rights of people with disability with respect to dignity. |
| Objective (xxiv) | (a) – (d) highlight the promotion of all cultural values and languages used in Uganda, including Sign Language which is used by persons with hearing impairments to preserve and enhance the dignity of all Ugandans. |
| Article 21 (1–4) | States that all Ugandans are equal before the law thereby going on to point out that no discrimination is allowed towards anybody, including people with disability among others.

The same article empowers Parliament to enact those laws aimed at redressing all sorts of social-economic and educational imbalances, and upholding a free democratic society. |
| Article 32 (–2) | Requires the state to take affirmative action and Parliament to enact relevant laws for the establishment of an Equal Opportunities Commission in favor of marginalized groups who are usually segregated by tradition, history and customs. |
| Article 35 (1–2) | People with disability shall enjoy protection both from the state and Parliament in order to realize their full mental and physical potential. |

- Article 59 (1–4) Clearly empowers all Ugandans above the age of 18 including people with disability to exercise their right to vote.
- Article 78 (1–4) Clearly states that people with disability are to participate in the composition, representation and procedures of Parliamentary activities.
- Article 180 (1–3) Provides for full participation of people with disability in the activities of Local Government Councils as part of the marginalized groups indicated in Article 32.
- Article 107 Spells out grounds of removal of leaders from office. One such ground is failure to perform and not mental or physical incapacity. The former is disability friendly, whereas the latter is not.

The five Members of Parliament (MPs) representing disabled people serve on various committees of Parliament. In line with the provisions of the Constitution, these MPs have managed to influence the inclusion of disability issues in the following laws:

- the Parliamentary Elections Statute, 1996;
- the Local Government Act, 1997 (leading to the election of some 47,000 disabled representatives across all local government levels from the basic village cell to the urban council);
- the Local Government Amendment Act, 2000;
- the Uganda Communications Act, 1997;
- the Land Act, 1998;
- the Uganda Traffic and Road Safety Act, 1998;
- the Uganda National Institute of Special Education (UNISE) Act, 1998;
- the Movement Act, 1998;
- the Children Statute, 1996;
- the Workers Compensation Act, 2000;
- the Presidential Elections Act, 2000;
- the Universities and other Tertiary Institutions Act, 2000;
- the Rules of Procedures of Parliament.

As a conclusion I highlight some of the challenges which imply a need for further advocacy work in both Zimbabwe and Uganda.

Challenges for Further Advocacy

Zimbabwe

Unlike Uganda, in Zimbabwe the representation of disabled people in Parliament between 1995–2000 was not underwritten by any law. It was based on a presidential decision influenced in part by a desire to be seen as including marginalized sectors, but also by other political interests

within the ruling party. In the current Parliament there is no such representation. After the ruling party nearly lost the last Parliamentary election, the President used his prerogative to appoint to Parliament those whose loyalty was patently to the ruling party, ZANU PF.

The disability movement is faced with the challenge of advocating through the constitutional review process for its representation to be guaranteed by law so that it is not based on presidential dictate.

Although it exists, the Disabled Persons Act of 1992 remains unresourced, and therefore impossible to implement. While the act demands an accessibly built environment and provides for penalties to defaulters, at the same it exempts government institutions from the same law. This is a good example of tokenism. Sometimes it is said that instead of having a bad law, it is better to have no law at all, as it is often very difficult to amend an existing law.

Uganda

Although persons with disabilities in Uganda have made substantial gains in representation, there are only five disability MPs to represent the whole country. Their overall constituency is therefore unwieldy. They require more resources than are normally allocated to MPs if they are to adequately serve their wide and varied constituency.

Adding to the problems, the provision of special equipment to facilitate the communication of MPs with visual and hearing impairments has been slow. MPs also have to contend with the high expectations of constituents which often leads to frustration.

Finally, the absence of a comprehensive disability policy impedes the ability of MPs to make ministers of government accountable for implementing disability plans through their operational programs. The implementation of provisions of the Constitution and Acts of Parliament is being frustrated by delays to establish the National Council on Disability, which further adversely affects the attraction of funds for disability programs from the consolidated revenue fund.

Bibliography

- Camay, P. & Gordon, A. J. (Eds.). (1998). *Advocacy in Southern Africa: Lessons for the future*. Fordsburg, Johannesburg, South Africa: Co-operative for Research and Education (CORE).
- Constitution of the Republic of Uganda*. (1995).
- Department for International Development, UK Government. (2001). *Disability, poverty and development*. London: Author.
- Development Initiatives and Services. (2001). *Workshop report on aging and disability*. Bulawayo, Zimbabwe: Author.
- Hunt, M. & Wade, S. (Eds.). (1999). *Exploring diversity issues within the international NGO sector* (Occasional Papers Series, No. 21). Oxford, UK: INTRAC.
- Local Governments Act*. (1997). The Republic of Uganda.

Manombe-Ncube, J. (2001). *The role of disabled people's organizations (DPOs) on aging and disability*. Paper presented at the Nairobi Workshop, March 2001.

National Union of Disabled Persons of Uganda. (1995). *Decentralization of NUDIPU through building cross disability coalitions at district level, and developing their capacity for self-management*. Kampala, Uganda: Author.

Parliament of Uganda. (2001). *Disability friendly provisions enacted by Parliament to date*. Paper presented at the National Conference for District Union leaders and Councillors for People with Disabilities, Mukono, Uganda.

Rehabilitation International, African Vocational Sub-Commission. (2000, December). *Newsletter*. Johannesburg, South Africa: Author.