

Disability stakeholders' perspectives regarding social development

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ABSTRACT

Since 1994 disability organisations, like other organisations in the country, have had to face significant transformation. While the disability sector achieved major successes in including issues surrounding recognition of rights of people with disabilities into policy frameworks, the challenge remains how to proceed to ensure that the implementation of these policies manifests in a way that includes people with disabilities within development frameworks.

This paper explores the perspectives of disability stakeholders regarding development, based on an electronic web discussion which was conducted as part of a broader project on disability and development. Findings revealed various challenges in the sector which are discussed in terms of the political stages of identity politics.

Key words: disability, mainstreaming, policy implementation, poverty alleviation, social development

Introduction

The focus on positive functioning, as described in the editorial, has implications for the broader context of intervention and rehabilitation. Perhaps one of the most significant implications is the focus on the strengths or capabilities of an individual, family or community and the need to understand the perceptions and interests of the people with disabilities themselves in facilitating the concept of all inclusive policy frameworks and implementation. It is therefore not surprising that much emphasis has been placed in the last decade on the inclusion of disability issues within mainstream policies and their implementation in South Africa¹. This is reflected not only in the education policies focusing on inclusion of children with barriers to learning¹, but also includes people with disabilities within the broader socio-economic development framework in the country².

This movement towards the inclusion of people with disabilities within mainframe policies and implementation necessitates an understanding of how people with disabilities themselves, and in particular disability stakeholders, view themselves within this process. One of the pivotal points in this process is the understanding of the link between poverty and disability which provides a strong impetus for the focus on more inclusive policy frameworks.

Disability and Poverty

Disability has been seen as both a cause and a consequence of poverty. This is because disability increases vulnerability to poverty, while poverty creates the conditions for increased risk of disability. For example, poverty increases vulnerability to disability through poor nutrition, lack of access to healthcare, greater exposure to violence and unintentional injuries, lack of knowledge of prevention, etc. Conversely, disability increases vulnerability to poverty because of the costs associated with disabilities, discrimination in the labour market, difficulties related to accessing education and assistive devices, etc³⁻¹⁰.

Studies conducted in the industrialised countries show that people with disabilities generally have lower incomes than non-disabled people. For example, surveys carried out in the United States between the 1950s and the 1970s showed substantial disparities between disabled and non-disabled people's incomes, with the average wage rates of disabled people about 60% of those of people without disabilities³. Using longitudinal data from the British Household Panel Surveys in conjunction with other studies conducted in the United Kingdom and Germany, Burchardt⁴ has systematically demonstrated the two-way relationship between disability

and poverty/social exclusion by pointing out that individuals in the lowest quintile of the income distribution were two and a half times more likely to become disabled than those in the highest quintile. She also found that the onset of disability was associated with an added risk of entering poverty, as well as "a decrease in the proportion of people leaving poverty" (Burchardt⁴ p.63). Although the data are less comprehensive, similar patterns have been identified in the developing countries, including South Africa^{11, 12}.

While less attention has been devoted to the ways in which disability and illness are intermediated by other inequalities including gender and race, the evidence suggests that other inequalities compound the social and economic disadvantages associated with disability. In general women with disabilities experience higher levels of discrimination and disadvantage than do men with disabilities^{3,13-16}. In the industrialised countries, for example, indicators of income, employment, education, social security and medical expenditure for people with disabilities show consistent gender inequalities¹³. Within industrialised countries such as the United States, race also plays an important role, with both disability and mortality rates strongly reflecting racial inequalities^{16, 17}. Within developing countries data on disability rates are more fragmented and less reliable, but indicate similar trends³.

These trends have profound implications for development. Besides providing *prima facie* support for dealing with disability in development, the cumulative impacts of other inequalities such as race and gender serve as further confirmation of the need for more integrated or inclusive approaches to poverty and disability. Furthermore, disability has not only been associated with poverty, but also with higher rates of mortality. For example, recent findings by the World Bank show that in some parts of the world, as many as 80% of disabled children die before the age of five, even in areas where the overall child mortality rate is under 20%³. This not only has implications for understanding the depth of deprivation among people with disabilities, but may also have resulted in the serious underestimation of the prevalence of disability in developing contexts. A further reason for focusing attention on disability relates to recent findings that people with disabilities have a two- to three-times higher risk of acquiring HIV/AIDS due to abuse and lack of information¹⁸.

In the South African context, there are a number of factors that add saliency to the relevance of investigating the association between development and disability. Firstly South Africa has a history of colonial subjugation, racial oppression, racial inequalities and poverty. The associations between poverty and disability are thus intertwined in complex

configurations. Within the context of changing policies and attempts to redress the injustices of the past, understanding the complex relationships between disability, poverty, gender and race are therefore vital for advancing the cause of disability and addressing poverty. Secondly, the country has a relatively advanced disability policy and a strong disability lobby. Thirdly, South Africa has a strong commitment to multi-sectoral development and intervention that favours an inclusive approach to development.

In order to investigate the issues outlined above a team of researchers, mainly from South Africa, embarked on a research project to assess the extent to which disability has been included within the current development policies, strategies and programmes of the major development agencies in South Africa. The project also aimed to explore the opportunities, constraints and potential strategies for the incorporation of disability as an issue, and people with disabilities as participants, within development policies, programmes and projects. As a first step in this process, it was decided to obtain information from disability stakeholders and interest groups on their views regarding the linkages between disability and development. The findings were interpreted within the framework of political stages of disability politics in an attempt to make sense of the current disability movement in South Africa.

The E-discussion

An asynchronous online electronic or e-discussion web forum was developed as a platform to consult with stakeholders in the disability sector. This week long e-discussion was proposed at a face-to-face meeting as it was felt that logistically it would be very difficult to get all important role players together. The information about the e-discussion was disseminated on the major disability email list servers in South Africa, such as Rehabilitation / Discussion (disability@lists.healthlink.org.za), National Accessibility Portal (NAPSA) (general@napsa.org.za), Augmentative and Alternative Communication (AAC) (aacs@kendy.up.ac.za) and The University of Pretoria (opforum@postino.up.ac.za; emaildir@kendy.up.ac.za; earlyint@kendy.up.ac.za; phdaac@kendy.up.ac.za) as well as on the Centre for AAC's website (www.caac.up.ac.za). In addition a list was compiled of all the disability organisations that were affiliated to the South African Federal Council on Disability, an umbrella body to which all the major disability organisations in South Africa are affiliated. Personal invitations for participation via email were also sent out to the directors of these organisations. In addition three members of parliament who represent people with disabilities in government were also invited to take part in the discussion. It was decided that discussion with the development sector would be undertaken at another time, when the project had generated more interest in the issues.

The e-discussion was titled "Including disability in the context of development" and was scheduled to take place over a week from 27th February 2006 to 3rd March 2006. However, participants continued posting comments up until 10th March 2006. Three Questions were posed for the duration of the discussion:

- **Question 1:** As a person with a disability or someone involved in the disability sector, what has your experience been of the relationship between disability, poverty and development? This question sought to obtain examples of interactions between the disability and development sectors and an indication of the extent to which the disability sector was interested in and had actively addressed development issues.
- **Question 2:** What can be done to mainstream disability in development and poverty alleviation policies, programmes and projects? With this question we sought to assess the extent to which development agencies, policies, projects and programmes in South Africa have addressed the issue of disability, as well as accessing the range of strategies that might be used.
- **Question 3:** In your experience, which development agencies or companies are already involved, or should be involved, with issues relating to disability? The aim of this question was to obtain an indication of disability agencies' awareness of the role players in development and more generally to assist in the identification of development agencies that were involved with disability issues.

Forty-six people registered to take part in the discussion. Of those who registered, 19 actually participated by contributing postings. The majority of these were researchers in the field of disability (n= 11), The

rest of the participants were made up of three representatives of national disability organisations, three rehabilitation professionals (n=1 OT, 1 PT, 1 Psychologist), one disability consultant and one disability activist in the area of eco-tourism. Of all 19 participants who contributed to the discussion, three members were people with disabilities.

Members who registered came from South Africa, The Netherlands, Belgium and Brazil. However the participants in the discussion were all from South Africa and were located mainly in Gauteng, Western Cape and Limpopo provinces.

There were 49 postings altogether in the discussion. Question 2 received the largest number of responses (26= 53%) followed by question 1 (12= 25%) and Question 3 (11=22%). The three authors who have extensive experience and research in disability, development and rehabilitation issues respectively, analysed the responses in two different ways. Firstly the third author analysed the responses to the three specific questions and provided a breakdown and synopsis of the important issues which were highlighted in each question. Thereafter the first and second authors independently either confirmed or clarified this analysis and synopsis. The results of this validation process can be seen in Tables I – III. Secondly, based on the above analysis, the three authors independently identified common themes across these questions and thereafter obtained consensus.

Themes from the discussion

The following summaries detail the range of responses obtained under each of the three questions or themes of the discussion.

Relationship between poverty and disability

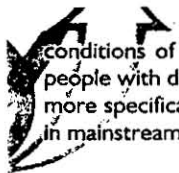
There was a general acknowledgement of a strong link between disability and poverty.

The reasons for this were:

- The high cost of being disabled in terms of health, devices and accessibility eg, specialised transport arrangements.
- Poor access to educational opportunities for people with disabilities leads to a lack of skills and therefore poor economic advancement.
- Related to the quality of special education for people with disabilities as very little emphasis is placed in schools on transition planning and preparing the young adult for employment.
- The overall lack of access that people with disabilities have to society in general and how people with disability therefore remained isolated and out of the mainstream.
- High unemployment rates in the country overall and people with disabilities having to compete within this market for employment.
- The issue of poverty in general in South Africa eg, 66% of all children in SA live in environments of poverty (INDS) thus increasing the risk of children suffering impairments.
- Poor access to disability grants.
- Continued fragmentation of the disability sector. This leads to confusion for those in the public and private sectors who wish to engage with the disability sector
- Lack of disability awareness as:
 - Government needs to be trained regarding the potential of people with disability.
 - Society in general needs to be more aware regarding disability to reduce the stigma and negative attitudes towards people with disabilities. Changing attitudes will seek to enhance chances of employment and impact on economic advancement of people with disabilities.

Table I : Responses to Question 1

From Table I it may be seen that the majority of the responses focused on issues relating to health costs, lack of access to civic life, transport and education, and lack of awareness of disability, as the major causative factors contributing to the relationship between poverty and disability. There generally appears to be a high level of awareness around the issues related to disability and poverty, but the issue of development and the relationship between development and disability were hardly addressed at all. Various comments pointed to the added burden of disability



conditions of poverty, and challenges relating to the employment of people with disabilities within a context of high unemployment. Table II more specifically addressed the issue of how disability can be included in mainstream development.

in development. This points to a need to improve the awareness of what development is and which agencies are involved in development work specifically related to poverty alleviation.

Mainstreaming disability into development

Some policies are in place (eg, the National Development Agency (NDA) 'developmental mandate' makes provision for primarily targeting vulnerable communities and individuals including people with disabilities) but there is a gap between policy and implementation. The reason is that governments often create policies as a symbolic gesture of identifying with universal values and seldom go beyond this symbolic level. This, however, points to the need for people on the ground to hold government and other institutions accountable and thereby to the need for organised activism.

Participants explored the reasons for the disability sector's failure to ensure accountability and to maintain its activism. These included:

- Fragmentation of the disability sector in the post-1994 period. The sector, it was argued, is currently not well-organised and had failed to adjust to post-1994 conditions. The sector was therefore characterised by:
 - Infighting and squabbling.
 - Competition for funding which exacerbates fragmentation. According to one participant: "Organisations are in survival mode." Competition over funds should not be happening, as sufficient funding appears to be available.
 - The South African Federal Council on Disability is therefore not operating as it should and the sector does not speak with one voice.
 - Organisations have developed within the framework of the top down medical model and therefore still see others as responsible for "solving" their problems. They feel disempowered.
- That there is a need for the disability sector to start looking inwards to address some of the following issues:
 - What are the unique claims of the disability sector? Why should the sector receive prominence in South Africa where a number of other pressing issues exist?
 - The sector needs to start "growing up" and see itself as a constituent rather than a patient. This will facilitate the integration of disability into the mainstream.
 - The disability sector has failed to evolve since 1996. It has not moved from being a sector that just demands to a "sector responsible for knowledge production on disability". The sector cannot achieve economic development if it does not take on issues such as "proactive analysis of policies and the evaluation of their impact".
 - The disability sector should also be focusing on an educative and awareness-raising role.
- Lack of mainstreaming of disability into society stems from attitudinal barriers that manifest as physical barriers. Attitudes in turn arise from a lack of knowledge and understanding. There is a need therefore for:
 - Empowerment of the disability sector so that it becomes assertive, independent and self sufficient.
 - Speaking with one voice not just as individual organisations.
 - The public, including education authorities and employers, needs to be educated about the realities of disability.
- As a result of people with disabilities being disempowered, the relationship between the disability and development sectors was impaired because:
 - Lack of unity within the disability sector discourages collaboration with the development sector.
 - The development sector lacks knowledge regarding the potential of people with disabilities as well as lack of skills. The Employment Equity Act is however a step in the right direction.

Table II: Responses to Question 2

From Table II it is clear that participants were frustrated by the lack of implementation of policies relating to disability and development. In addition, participants questioned the capacity of the disability sector to deal with the issues in a proactive way. The need was thus identified for disability organisations to engage in the process of introspection in order to move forward. More responsibility should be taken by the sector to work towards strategies to include people with disabilities within the mainstream. Demand-driven approaches need to be augmented by the acknowledgement of the responsibilities that are implied by both partners as part of the process of integration and inclusion. From this, the need for focusing on disability awareness and education of people working within development organisations, government structures and the general public was emphasised.

It is also clear from the discussion that there is a lack of understanding among some of the participants of what constitutes the development sector and how to initiate dialogue between the two sectors. The responsibility for development seems to be laid squarely on the shoulders of government. Important questions were raised, however, about the disability sector's need to re-examine the ways in which it operates and the messages that it sends to society. In addition to looking at the efficacy of practices in the disability sector, the discussion also emphasised the need for the sector to take on the role of knowledge dissemination.

In congruence with information in Table II, Table III also reflects confusion or a lack of knowledge in terms of what development agencies are and the projects they are involved in. The perception is that it is mainly government and private companies that are involved

The identification of development agencies already involved and those that should be involved

There appeared to be a general lack of knowledge with regard to the role and scope of development agencies. The following issues were highlighted:

- Government was the main role-player identified in the development sector.
- Development agencies were perceived as having a lack of awareness of disability and the potential of people with disabilities. The perception exists that funding agencies regard investment in disability organisations as a waste of money.
- The perception was that collaborating with the disability sector does not always fit in with development agencies' perception of pay off in terms of visibility and recognition.
- There is an awareness that the disability sector needs to organise itself in terms of being an advisory service within its liaison with the public and private sectors. In terms of the public sector it should liaise more closely with The Office on the Status of Disabled People (OSDP) and in the private sector with organisations such as CHAMSA (Chambers of Commerce and Industry South Africa).
- The disability sector needs to become more knowledgeable about the issues of development and development paradigms.
- There is a need for the disability sector to be responsible for evidenced-based research and surveys in order to strengthen its arguments when dealing with development agencies.

Table III: Responses to Question 3

Discussion: Reflection on political stages

In conclusion, the major themes which emerged from the discussion and interactions relating to the three questions posed will be summarised and integrated.

Perhaps the most prominent theme that emerged related to the fragmentation of the disability sector and the need for this sector to engage in self-reflection and unification for future growth and development. This step seems to be most important in enabling the sector to face the challenges that were raised.

The issue of disability awareness-raising in the public and government sectors still seems to be a major challenge. The development of a better understanding of what it means to be a person with a disability and how this translates into the social and employment contexts in terms of support and opportunities is a high priority in addressing discrimination and attitudinal barriers.


Another issue relates to the relative lack of understanding and interaction between disability organisations and development agencies. Government seems to be identified as the main (if not only) development agency and this tends to focus all attention and responsibility for accommodation of people with disabilities on government. While government certainly has an important role to play in this process, the participation of the disability sector is vital in ensuring consistent and sustained interactions on topics of concern.

It is, however, also important to locate these findings within the broader context of the disability movement and disability politics. Fraser¹⁹ proposed three stages in the political development of the new social movements that emerged in the latter half of the twentieth century. Firstly, there is the struggle over the political status of a given need. The second stage involves debates over the interpretation and definition of the need, while the third stage focuses on the struggle for the satisfaction of the need. It is clear from the legislative framework created in South Africa since 1994 (for example, the Constitution of South Africa²⁰, the White Paper on an Integrated National Disability Strategy (INDS)²¹, and the Employment Equity Act²¹) that there has been significant progress towards recognising the political status of disability in this country. There also seems to be an emerging consensus on the association between disability and poverty. Although the need to include disability issues within the broader development framework has received some support, more needs to be done to facilitate this process. The fragmentation, which is currently evident in the disability sector, can be seen as a product of the lack of direction in terms of specific strategies for moving forward in relation to the satisfaction of the need to mainstream disability into development.

Building on Fraser's three stages, Shakespeare and Watson²² (p.547) highlighted three elements that are important in identifying the types of political claims that are being made in the context of disability politics. Firstly, there is the claim that people with disabilities are a disadvantaged or marginalised constituency, a case for which evidence is steadily increasing and which has been acknowledged by some of the major development agencies in the world.

The second element relates to the claim that people with disabilities form a distinct minority and should themselves initiate and lead social change for their group. This element puts identity politics at the centre of the new movement. Although it is historically clear that disability groups did play a major role in gaining political recognition, the question can be asked whether the lack of unity in the disability sector might not reflect a failure of identity politics, indicating a need for redefinition of the sector in terms of who they are and their associations with other vulnerable or oppressed groups.

The third component identified by Shakespeare and Watson²² refers to the social model of disability. In this model, disability is defined as the way societies deal with people who have physical impairments. People are therefore disabled, not by their bodies, but by the barriers societies erect against the social inclusion of people with disabilities. The findings from the discussion certainly indicate a general understanding of the social model among those participating in the discussion, however, it also demonstrates the lack of knowledge that exists in the disability sector in terms of what the nature of the new paradigm implies for practice in terms of inclusion in mainstream development activities. The intimation that the South African disability sector has not successfully adapted to the new context in which it finds itself is evident throughout the discussion, but it is perhaps most clearly stated in the following excerpt from the discussion:



The New South Africa has evolved in many ways politically, socially and economically, but the disability sector has not. We are largely stuck in a pre-1994 approach to development. Ten years later, we have not made the transition from being a sector that demands, and rightly so, policy inclusion at every level of government to a sector responsible for knowledge production on disability, a sector that values its own intelligentsia.

Reasons for the general failure of the disability sector to meet the challenges of the current context of disability and development may be sought both exogenously and endogenously to the disability sector. In terms of the former, it has been argued that civil society as a whole has experienced difficulties in adapting to post-1994 conditions²³. Since 1994 the disability sector has had to face a number of new challenges. These included substantial losses in funding as donors began channelling their funding to the new democratic state rather than civil society organisations as they had done during the apartheid years. In addition to losses of financial support, civil society organisations also experienced losses in leadership and capacity as people who had previously worked in the sector took up positions in the post-apartheid state, both because of the greater acceptability of the state and financial insecurity in the civil society sector. With the post-apartheid state's more supportive role to disability, many new disability-related positions were created in government and filled by people who had played a leadership role in the disability movement.

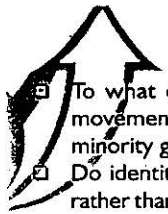
The end of apartheid and the establishment of a democratic state required a radical adjustment by civil society, resulting in confusion and a loss of direction by many of the organisations that made up the sector. *"Prior to 1994 the focus of the Non Governmental Organisations (NGOs) was to organise and support resistance to the apartheid state. Many NGOs became rudderless when a democratic dispensation came into being. Instead of focusing on what the democratic government was unable or unwilling to do they attempted to continue with their old tasks, often duplicating the functions of, especially, the local state"*²³. For the disability sector, reforms such as the Integrated National Disability Strategy, published as a White Paper in 1997²¹, also required a radical change of direction by the disability movement.

The impact of these contextual factors on the disability sector needs to be assessed in conjunction with the endogenous characteristics of the disability movement, especially in terms of what Shakespeare and Watson²² call the *"complexities and contradictions of disability politics"* (p.557). Traditionally, disability has been divided (in terms of the medical model) into specific groups of impairments, and organisational structures have tended to coalesce around these essentially medical diagnoses and groupings. **A central thrust of the disability movement was to emphasise commonalities, in terms of oppression and social exclusion for example, between the different impairment groupings, and thereby to encourage the development of umbrella or cross-impairment groupings.**

However, while it is important not to underestimate the significance of cross-impairment commonalities, it is inescapable that specific needs and interests are also associated with the different impairment groupings in terms of service requirements, assistive devices, and even in terms of the barriers and exclusions of societies that they experience. For example, on the global level the deaf community has not always identified with the mainstream disability movement because deaf people often see themselves as a linguistic minority using sign language. The deaf community has also tended to reject the mainstream demand for inclusive education, preferring to have its children educated separately through the medium of sign language²².

Recent years have seen the decline of the South African Federal Council on Disability (SAFCD) to a shadow of its former self in the final years of apartheid and the early years of the post-apartheid state²⁴. While cross-impairment organisations still exist in South Africa and may still be playing important roles in disability politics, currently the most robust disability organisations in South Africa appear to be those that have organised themselves around specific impairments. Shakespeare and Watson²² directly and indirectly pose a number of other questions about disability politics that may have relevance to the South African disability sector. These include:

²⁴ The decline of the SAFCD has been attributed to both the loss of funding and 'in-fighting'.



- To what extent does the diversity of interests in the disability movement have the potential to undermine "the idea of a disabled minority group"?
- Do identity politics "reinforce disabled people's status as different rather than truly to open up the mainstream to the inclusion of people with impairments"?
- How representative is the disability movement, particularly in relation to the aged and the underprivileged or marginalised?
- To what extent has the disability movement made a difference to people living in poverty?
- To what extent is the disability movement able to accommodate other social cleavages such as gender, race, ethnicity and sexual orientation?
- How widely has the social model been diffused and adopted?

Conclusion

These questions are not raised as 'criticisms' of the disability movement in South Africa or abroad, but rather in the context of the challenges facing the South African disability sector and its need to reassess its position in the face of these challenges. In this regard, it would appear to be important that disability organisations invest effort in developing a better understanding of their own unified identity to allow them to move forward with strategies for inclusion into the broader spectrum of socio-economic development and poverty alleviation. For development in the country to be effective requires that it be an inclusive concept. This requires that disability organisations become more focused on talking to those stakeholders who have not traditionally been part of the disability movements. Only by raising awareness and consciousness of the importance of an inclusive development policy can we move towards reducing the barriers in society experienced by people with disabilities.

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References

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