Section 3

Disability Studies

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chapter ten

Disability and the Deficit Discourse: The equity challenges for South African higher education

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Introduction

In July 2001, the Ministry of Education published White Paper 6 (DOE 2001a) entitled 'Special Needs Education: Building an Inclusive Education and Training System'. This policy outlines the Ministry's commitment to the provision of educational opportunities for 'those learners who experience or *have experienced* barriers to learning *and* development' and as a result have either been excluded from accessing existing education provision or have dropped out of the learning process (DOE 2001a: 6). White Paper 6 (DOE 2001a) asserts that these inequalities have arisen because of a failure on the part of the system to meet '*a broad* range of learning needs (that exist) among the learner population in any point in time' (DOE 2001a: 17). The system's inability to accommodate particular learning needs results in some learners either being excluded from the system as a whole or in experiencing learning difficulties within the classrooms or lecture theatres which prevent effective and sustained access to the curriculum (DOE 2001a: 6). The policy places particular emphasis on addressing the needs of learners with disabilities who are recognised as having been most vulnerable to the inequalities described above.

The changes outlined in the policy document represent, as the Minister acknowledges, a 'landmark' in the history of education in South Africa

(DOE 2001a: 4). Not only do they seek to address some of the most unrecognised inequalities of the apartheid education system, but they also challenge fundamental assumptions about teaching and learning and the manner in which particular groups of learners are discriminated against in accessing existing educational provision or in participating equally in the classrooms. Of particular importance is the assertion that, in order for all learners to participate in and obtain equitable benefits from the education system, there is a need to recognise and provide for the full range of learning needs that exist among learners in the country. This challenge involves systemic change where change strategies are orientated towards building the capacity of the system to accommodate a diverse range of learning needs. This involves recognising and addressing the barriers that lead to exclusion and learning breakdown and providing additional support to those learners who may require it to ensure effective learning (NCSNET/ NCESS 1997).

Such capacity is built and sustained through adherence to principles of flexibility in the organisation and functioning of education systems as well as in teaching and learning practices so that a range of learning programmes and approaches can be provided within a single, integrated system. It acknowledges the importance of equal and mutual respect between educator and learner and of the need to address historical bias and prejudice through the process of teaching and learning. However, it also recognises that the provision of support is an integral part of the delivery of education services. Such support is directed towards barriers to learning that already exist, preventing barriers from occurring as far as possible and ensuring that all aspects of the curriculum are flexible and accessible to all learners. However, it also has a second and related focus which is on ensuring that all aspects of the educational institution's functioning are responsive to diverse needs – from the values and norms that give rise to the culture of the institution to the policies and processes that inform its daily functioning: together these strategies for change provide the framework for an inclusive education and training system.

The importance of understanding ongoing exclusion and learning breakdown in this way is especially important for schooling and it is this band that is given most attention in White Paper 6 (DOE 2001a). However, both nationally and internationally, there is a growing recognition of the importance of understanding exclusion and learning breakdown within higher education in the same way.[1] Within this paradigm, higher education institutions should be organised and should function in such a way that they are able to provide for the full range of learning needs within the student population. To do this, attention needs to be paid to all the issues noted above, including the provision of enabling mechanisms such as particular forms of academic development or learning support as integral to the functioning of the institutions and directed towards the system as a whole – the institution as well as educators and students where such support is required.

I argue that while building such capacity in higher education is central to the creation of equity, the challenges that it poses for institutions are significant and require them to tackle difficult questions around institutional transformation. Particularly important are those that point to the nature of teaching and learning and knowledge production as well as the provision and organisation of academic development and learning support. These areas of focus draw attention to the functioning of the institutions themselves and conditions within that facilitate or hamper opportunities for equitable participation and therefore fair chances for the attainment of equitable outcomes. While the National Plan for Higher Education (DOE 2001b) recognises the interrelatedness of equity of access and equity of outcomes and the central role of enabling mechanisms such as academic development in facilitating the latter, this understanding has not been sufficiently linked to meeting the full spectrum of learning needs which exist among the learner population.

If the equity imperative is to have meaning for particular learners, we need to move beyond limited understandings of access to recognising and interrogating the complex and full nature of exclusion within higher education. This involves addressing the challenges of building an inclusive higher education system in South Africa. In turn it requires us to explore the key recommendations and challenges arising from White Paper 6 (DOE 2001a) within the framework of the National Plan (DOE 2001b) and the Ministry's more recent policy framework for a New Institutional Landscape for Higher Education in South Africa (2002). In line with the emphasis given in White Paper 6 (DOE 2001a), this chapter explores the issues of inclusivity and equity in higher education primarily from the perspective of students with disabilities. It attempts to show that the nature and extent of the inequalities experienced by learners with disabilities provides insight into the barriers, particularly at the micro level of the institution, which impact on educational inequality in general.[2] More importantly, however, it attempts to show that in fact, the creation of equity for all learners in higher education requires that we move away from categorising learners and start developing institutional practices that respond to perceived needs within such categories. Rather, we should shift our attention towards developing the capacity of the system to accommodate the full range of diverse learning needs, irrespective of the 'category' into which the learner fits.[3] This forces us to turn our attention to the nature of the barrier, how it manifests itself in restricting access or hampering the teaching and learning process and then to find ways to ensure that the curriculum is accessible to all learners, including, but not limited to, the provision of a continuum of learning support provision.[4]

The historical legacy and challenges for higher education

Post 1994 policy and legislation on higher education in South Africa has emphasised the need to overcome previous inequalities in the system. Of particular concern has been the commitment to increase access to higher education for previously disadvantaged learners. Proposed changes are located within an equity paradigm where recognition is given to the need for redressing previous inequalities and creating a fair and just higher education system. It has also been asserted that changes are needed to the way in which existing higher education institutions are structured and function so that they can begin to accommodate and meet the educational needs of a larger, more diverse student population.

Although the student profile in universities and technikons has changed significantly over the last ten years (Cooper and Subotzky 2001: 18), increasing access has largely been focused, as can be expected on issues of race and gender, with the latter perhaps receiving less attention. To date, the process of policy implementation and institutional transformation has focused little attention on moving beyond these two distinctive 'categories' to focus on what the National Plan identifies as 'non-traditional students' (DOE 2001b: 28). Included among these are learners with disabilities who have historically been most vulnerable to exclusion and marginalisation throughout the education system.

For learners with disabilities in particular, inequalities evident in higher education can be linked to those that have shaped the schooling system in South Africa. At this level, education provision was separated not only on the basis of race, but also on the identification and categorisation of learners into those who were regarded as 'normal' and those who were seen to have 'special needs'. This latter category of learners included all those learners who were unable to 'fit in' to the dominant mainstream system. In reality this tended to encompass a wide range of learners including those with different disabilities, those who were perceived to have learning difficulties or behavioural problems as well as those who were in trouble with the law. Educational provision that existed for these learners was also racially divided and inadequate for the need that existed, especially for black disabled learners.

The levels of deprivation and exclusion experienced by learners with disabilities, especially black disabled learners, was so severe that in 1997 the Integrated National Disability Strategy for South Africa (INDS) estimated that approximately 70% of learners with disabilities of school-going age were outside the general education and training system (Office of the Deputy President 1997: 37). For the few, more privileged learners with disabilities who were able to attend special schools, other problems inherent in a separate, peripheral system were evident. In some schools the curriculum was inappropriate for preparing learners for the world of work, with only some special schools offering tuition up to matriculation level (DOE 1998: 25). Despite improvements in the last five years, White Paper 6 (DOE 2001a) still estimates that between 260 000 and 280 000 learners with disabilities are out of the school system (DOE 2001a: 16). The lack of appropriate and adequate provision for learners with disabilities at the schooling level has had a profound effect on the number of disabled learners who have been able to access post-secondary educational opportunities. The Integrated National Disability Strategy for South Africa (INDS) argued in 1997 that although no reliable statistics existed at that time, higher education largely remains out of reach for the majority of learners with disabilities (Office of the Deputy President 1997: 38). The lack of reliable data in this area was confirmed by the Council for Higher Education (CHE) in their 2000–2001 report. It is therefore difficult to get an accurate picture of the level of exclusion of these learners. The Council points out, however, that even if 10% of those learners with disabilities who are presently in the schooling system

> were to enroll in HE, this would represent a significant challenge for institutions at the levels of infrastructure, support services and learning and teaching' (CHE 2001: 27).

The barriers to accessing higher education arising from the schooling system are exacerbated by inequalities inherent to higher education in South Africa. The impact of other barriers within higher education institutions themselves continue to substantially limit the ability of these students to participate equitably in the learning process and thus have the opportunity to achieve equitable outcomes and benefits. These barriers relate directly to:

- attitudes to disability and learning;
- academic curricula;
- the physical environment of institutions;
- the organisation, focus and provision of learning support and academic development programmes;

- the allocation and distribution of resources;
- as well as the role that higher education plays within the society as a whole.

Wolfendale (1996), in discussing the higher education system in the United Kingdom, argues that in general higher education reflects a level of the education system which is associated with processes of rigid selection 'which filter(s) out the eligible few from the ineligible many' (Wolfendale 1996: 1). Davies et al (1997) argue that understandings of 'eligibility' are strongly defined, reproduced and legitimated through a dominant discourse which gives meaning to the 'purpose' of higher education in a society and the institutional practices which support this 'purpose' (Davies et al 1997: 16). Particularly in the era of globalisation, the emphasis on the development of skills and knowledge that are seen to be necessary for and dictated by the market directs teaching and learning towards the attainment of these goals. Learners who are regarded as being unable to compete in this market are not seen as a priority in terms of curricula responsiveness, learning support and the allocation of resources.

For learners with disabilities in South Africa, their 'eligibility' for higher education, both in the past and the present, is substantially influenced by perceptions of what they are capable of as people with disabilities. Thus students with disabilities have reported being denied access to particular courses because they are believed to be unable to meet the course requirements. Examples cited include courses involving field work, practical professional development in off-campus facilities, courses that entail the studying of graphic material or the use of particular equipment and courses which require extensive interaction with the public (Odendaal-Magwaza and Farman 1997: 2).

This supposed 'ineligibility' can be directly linked to the dominant discourse of disability and 'special needs' which, as has already been argued, provided the basis for a segregated and inadequate schooling system. So while higher education institutions have not been separated into 'special' and 'ordinary' institutions, the dominant medical discourse of disability (Fulcher 1989) and its attention to individual deficit, has placed the emphasis on the nature of the learner's impairment and the extent to which this impairment is perceived to limit particular capabilities, including academic pursuits. The criteria for ineligibility are seen to arise from the learner's own personal problems or circumstances (the existence of a disability such as Deafness or Blindness) rather than institutional criteria and practices. Barton and Oliver (1992) argue that the location of the 'problem' with the learner rather than the institution and the associated medical emphasis serves to depoliticise this area and remove if from public debate and accountability (Barton and Oliver 1992: 68).

The dominant medical discourse of disability and attention to individual deficit has also influenced the nature and provision of learning support systems for learners with disabilities where they exist in South African higher education institutions. While some institutions have attempted to respond by providing some support services to students with disabilities, the 'disability units or desks' that exist vary considerably in the work that they do and the services that they offer. In many cases they are also beset with resource constraints that limit the nature and extent of the services that they are able to offer. Most importantly however, where they do exist they tend to operate separately from broader academic development or learning support initiatives. Where some link exists, the collaboration is mostly with student health or counselling services rather than with those dealing directly with teaching and learning such as academic development programmes (CHE 2001: 69). This structural separation of learning support for students with disabilities from other learning support initiatives aimed at facilitating access to the curriculum, also absolves the academic development programmes from grappling with how to accommodate the learning support needs of all existing or potential students.

While some learners with disabilities will always require additional, more cost-intensive support to access the curriculum, such support should still be seen as part of a continuum of academic development services and integrated into the general academic planning process. In attempting to theorise learning support in higher education Simpson (1996) argues that an important distinction exists between learner services and those orientated towards what he calls 'learning development' or support in accessing the curriculum. He suggests that while both are important for effective learning, there needs to be a clear institutional distinction between the two. The latter must be delivered at the course and programme level, including 'the additional support that some students will need' (Simpson 1996: 24). In South African institutions at present where support services for students with disabilities do exist they fall clearly within 'learner services' rather than 'learning development'. The barriers already described have been further exacerbated by higher education institutions that remain largely physically inaccessible to many disabled students, especially physically disabled and Blind students.

For Blind and Deaf students in particular, access to information has also been extremely limited. Barriers arising from the curriculum have been evident in the methods and materials of teaching and learning used, the manner in which classes and learning have been managed and organised, as well as the nature of the assessment practices used within the institutions (DOE 1998: 16). The lack of flexibility in the teaching and learning process has become especially evident in the large number of students, especially those from historically disadvantaged backgrounds, who experience language and academic literacy barriers in the teaching and learning process. Lack of participation by people with disabilities in decision-making processes and structures within institutions has further marginalised these issues from debate and discussion in institutional planning and resource allocation. These barriers have a profound and sustained effect on the psychosocial well-being and functioning of the learner. People with disabilities who have managed to attend higher education institutions argue that the energy, emotional resources and levels of stress involved in dealing with the overwhelming range of barriers that confront them are extremely undermining and place them at an ongoing disadvantage to other learners. This in itself forces them to perform at a level not expected from other learners and when they are unable to do this, the prevailing attitudes and prejudices towards their abilities are reinforced. The barriers which learners with disabilities experience in higher education institutions therefore contribute directly to negative attitudes among staff and students towards their participation in the institution.

Taking the challenge forward in higher education

Making the conceptual link

The experience of students with disabilities in higher education up to now shows that the levels of inequality extend far beyond merely accessing existing provision within institutions. Although gaining access, especially to a career of the student's choice, is fundamental to the creation of equity for these students, being able to participate equitably in the process of teaching and learning, and achieve equitable outcomes from the higher education system remains as important as the former imperative. It is these latter considerations that provide the most substantial and far-reaching challenges for higher education institutions. Changes are needed not only to the physical environment in which teaching and learning takes place, but also to the way in which academic curricula are organised, delivered and assessed. Similarly, there is a real need to address attitudinal barriers at all levels of the institution that continue to locate the 'problem' of disability with perceived limitations or 'deficiencies' in the learner rather than the limitations of the system with its inability to meet the full range of learning needs among the learner population. This involves interrogating and addressing issues of diversity in all aspects of organisational life within the institution. Central to these areas of concern is the importance of an integrated and committed response to the provision of learning support systems, including more specialised ones, which are targeted at the process of teaching and learning and that aim to enable all learners to engage equitably with the academic curricula.

Implementing and bringing about such changes requires an ongoing commitment to these imperatives from both the Ministry as well as the institutions themselves. However, if the changes are to be sustainable and effective, the process of transformation needs to be realistic and recognise the constraints presently impacting on the sector as a whole and on institutions themselves, especially the historically disadvantaged ones.

While the key components of an inclusive system and their associated implementation challenges are dealt with at some length in relation to schooling in White Paper 6 (DOE 2001a), the higher education band is also given some attention. The policy makes reference to the National Plan for Higher Education (DOE 2001b) where institutions, in their strategic planning processes, are expected to indicate how they intend to 'increase the participation of learners with special education needs' (DOE 2001a: 42). The White Paper also states that the Ministry will make recommendations to higher education institutions 'regarding minimum levels of provision for learners with special needs' (DOE 2001a: 31). It is important to note that the policy states that while all higher education institutions will be expected to ensure that 'there is appropriate physical access for disabled learners' the provision of more specialised, cost intensive support that may be needed by some disabled students will be organised on a regional basis (DOE 2001a: 31).

The National Plan (DOE 2001b) outlines 'strategic interventions and levers' that in bringing about necessary changes in the system will certainly contribute to improving the participation of learners with disabilities in the sector (DOE 2001b: 5). Similarly, a commitment is made in the Plan to ensure that institutions prioritise increasing access for learners with disabilities. However, as already indicated, the interventions linked to academic development and learning support that the Plan describes do not go deep enough in explaining how such interventions can be used to reach the most vulnerable learners, especially learners with disabilities. Although it may be argued that if the framework for change outlined in the Plan is read, understood and addressed in conjunction with White Paper 6 (DOE 2001a) and its imperatives for higher education, then sufficient direction exists to ensure equity of access and participation for learners with disabilities. While this may be true, more attention certainly needs to be given to synergising the imperatives of the two policies, and the symbolic commitments made in the National Plan should be translated into clear directives. At best, this has not yet happened and taking the recent issues confronting the sector, the lack of attention to this area may be understandable. A scenario that evokes more concern is that at a conceptual level the link between building an inclusive education system as outlined in White Paper 6 (DOE 2001a) and the commitment to recognising the equal importance of equity of access and outcomes in the National Plan is not being made. It is essential that this link is made if equity for learners with disabilities is to be achieved in higher education.

Developing appropriate learning support systems

The area in which most thought needs to be given towards synergising the imperatives of the two policies is in the area of learning support and particularly the provision of the learning support needed by some students with disabilities. White Paper 6 (DOE 2001a) recognises that for some learners with disabilities, in particular Blind and Deaf learners, the provision of support to enable these learners to access the curriculum effectively may be fairly cost intensive (DOE 2001a: 28).[5] It is therefore recognised that where such learners require additional support such as Brailling or taping facilities or Sign Language interpretation, an effective strategy for regional collaboration around the provision of such services should be explored. This imperative stated by White Paper 6 (DOE 2001a) draws directly from a central principle outlined in the National Plan (DOE 2001b) where the need for regional collaboration by institutions is strongly articulated. Although the ideal would be for each higher education institution to have the capacity to meet the learning needs of all learners who may be admitted, including those that require more specialised, cost-intensive support to do this, the present financial constraints experienced by institutions may mean that, certainly in the short-term, such provision by each institution is not possible. Thus the notion of all higher education institutions becoming 'full-service' institutions is, certainly in the short-term, unrealistic and too cost intensive for consideration.[6] While it may be difficult at this stage for institutions to begin to grapple with the implications of the implementation of such collaboration, the organisation and provision of additional support services at a regional level is extremely important in the application of a non-discriminatory policy towards the admission of learners with disabilities and, more broadly, in the creation of equity. At this stage direction towards the operationalising of such regional collaboration in the area of support services has not been provided by the government. The Minister's May 2002 press statement, in response to the report of the National Working Group on the restructuring of the higher education system, states:

> Institutions would have to develop regional strategies to promote the access of disabled students. As a first step, the Ministry intends identifying three institutions that could become the focal point for the development of infrastructure and resources to cater for the needs of disabled students (Asmal 2002).

Although the statement demonstrates a commitment on the part of the government to support institutions and a re-emphasis of the importance of regional collaboration in this area, the notion of three institutions becoming focal points is cause for some concern. This concern is perhaps best illustrated by discussing possible options that might be considered in the operationalising of a regional approach to the provision of more cost intensive support services. If the notion of focal points is conflated with 'full-service' institution then the concerns outlined in option one become important to consider. However, if on the other hand 'focal point' is seen to refer to 'effective regional collaboration' (the second option discussed), then the commitment expressed in this statement reflects a positive attempt to take forward the equity imperative for students with disabilities.

OPTION 1: DEVELOPING A FULL-SERVICE INSTITUTION IN THREE REGIONS[7]

In this option one institution within the designated region is chosen and, through support from government and other higher institutions in the region, it can develop its capacity to become a full-service institution. This would meet the needs of all those learners in the region who may require more specialised support to access the curriculum. Although this is a possible way of providing necessary provision at the regional level, it is a problematic option if student choice is considered and the Constitutional imperative of non-discrimination is recognised. While the decision by any student about where they wish to study and the programmes they wish to pursue is constrained by institutional admission requirements, financial means and institutional programme diversity, much has been done since 1994 to ensure that all students who are eligible for entry into higher education can exercise some choice in making such decisions. If a particular student only has the option of attending one institution in the region because that institution is the only one that is able to offer them the support they require, their choice of programmes for study is severely restricted. This not only limits their career options and therefore their ability to compete in the labour market, it also means that their disability is used as the main reason for restricting their access to particular institutions.

This option also needs to be considered in the light of the principle of diversity through mission and programme differentiation across institutions (DOE 2001b). This imperative has been consistently articulated as central to a transformed higher education system since the report of the National Commission on Higher Education in 1996. The National Plan (DOE 2001b), drawing from the White Paper on the Transformation of Higher Education (1997) and the 'Size and Shape' report (2000) of the CHE, emphasises the importance of this principle for increasing and broadening participation by a more diverse student population and in meeting the human resource and knowledge needs of the country (DOE 2001b: 50). If students with disabilities are restricted in institutional and programme choice in the manner discussed above, then the option of full-service institutions presents a clear policy tension. While the aim is to provide for a more diverse student population through broadened participation, 'full-service' institutions will mean that students with disabilities will not be able to benefit from the differentiation offered by the system and their level of participation will be restricted.

OPTION 2: EFFECTIVE REGIONAL COLLABORATION IN THE PROVISION OF SUPPORT SERVICES

A central tenet of White Paper 6 (DOE 2001a), in developing an inclusive education and training system at the schooling level is the organisation and provision of support for schools, educators and learners at the district level. The policy makes provision for district-based support teams made up of a range of staff and resources that can be used to develop the capacity of all schools and the other education institutions in the district to meet a greater diversity of learning needs (DOE 2001a: 29). It is this principle of a collaborative approach to support provision to ensure access to such services by a range of institutions that is important for consideration by the higher education sector.

With this principle in mind, the second option for regional collaboration is to ensure that all forms of necessary support are available to a student, not at a specific, individual institution, but at the regional level. This could be achieved if each institution in a region is tasked with the responsibility of developing its capacity to provide a particular kind of specialised support. Although such support would be physically located at a particular institution, it could be accessed by any student in the region and thus used by any of the institutions. For example, one institution in a region may be assisted to develop its capacity to fully meet the academic needs of Blind students through appropriate Brailling, taping and specialised computer equipment. Another institution in the region may develop its capacity to provide appropriate Sign Language interpretation services. Both the visual impairment services as well as the Sign Language provision could be accessed and used by any Blind or Deaf student in the region, whatever institution they attend. This follows the district support team model where services are provided and shared at the district level. More importantly, however, it ensures that students with disabilities, by having access to a service which is operationalised at the regional level rather than institutional level but which can be utilised across all institutions, will be able to benefit equally from the diversity of programmes and courses offered within the region. The emphasis is then placed on developing effective support services across regions rather than on creating full-service institutions.

Although the practical implementation of such a system will require a comprehensive process of research and investigation, capacity building and most importantly, consultation, it is important to recognise its implications for ensuring that in accessing programmes of their choice, learners with disabilities are not discriminated against on the basis of their learning needs.

Minimum levels of provision: what else needs to be considered

In this chapter I have emphasised the area of learning support as central to the creation of equity and to discuss in some depth the problems that exist at present within the policy framework in this area. However, as pointed out earlier, other areas of concern are equally important in building an inclusive higher education system. Particularly important are the areas of curriculum flexibility and the accessibility of institutions to ensure a 'barrier-free physical and psychosocial environment' (DOE 1998: 126). White Paper 6 (DOE 2001a) argues that one of the most significant barriers to learning is the curriculum itself. It is argued that in addressing the ways in which it can serve to marginalise particular learners, the curriculum needs to be understood in its entirety. It argues that this includes: what is taught, the language or medium of instruction, how lectures are organised and managed, the methods and processes used in teaching or lecturing, the pace of teaching and the organisation of time, the learning materials and equipment used, as well as, and most importantly, how learning is assessed (DOE 2001a: 19).

For higher education institutions in particular, considering the highly individualised nature of teaching, much attention needs to be paid to the extent to which the academic curriculum is really accessible to all learners. While this requires commitment and awareness from lecturers themselves, it also involves attention to this area in academic planning and especially the processes used to evaluate and assess student performance. As already indicated, appropriate learning support mechanisms should be orientated towards providing this kind of systemic support. The extent to which attention is paid to the accessibility of the curriculum to all learners is directly linked to the level of respect that is given to accommodating diversity within the institution. Although the White Paper 3 on Higher Education Transformation (1997) and the National Plan (DOE 2001b), as well as institutions themselves, express a commitment to the accommodation of a more diverse student population, such a commitment needs to be taken further than at the level of rhetoric. This means that the Constitutional imperative of non-discrimination, particularly on the grounds of disability, needs to be integrated into all aspects of an institution's functioning, particularly in the policies and practices that govern the academic project of the institution. This should include for example the application of non-discrimination principles and practices in areas such as admission criteria.

Creating a non-discriminatory environment that truly respects diversity must of necessity, taking our history, involve the planned application of processes and initiatives to break down prejudice among all stakeholders in the institution. Institutions should actively campaign to promote the value of diversity in the institution and promote its benefits to the society as a whole. Of particular importance here is the role which higher education needs to play in creating the pool of graduates that will contribute to a more diverse labour force, a key objective of the Employment Equity Act (1997). Respecting diversity within the institution's community through non-discriminatory policies and practices and addressing prejudice remains central to overcoming the attitudinal barriers that continue to exclude and marginalise learners with disabilities.

Respect for diversity also extends to addressing physical barriers that limit mobility and thus access to institutional services for some disabled students, especially physically disabled and Blind students. As already mentioned, White Paper 6 (DOE 2001a) states that, while the Ministry will make recommendations on minimum levels of provision and regional collaboration relating to the provision of support services, all higher education institutions '**will** be required to ensure that there is appropriate physical access for physically disabled learners' (DOE 2001a: 31). This is likely to be of some concern to most institutions where understandings of physical accessibility are associated with expensive alterations and adaptations to the built environment of campuses. While there are obviously some cost implications for developing accessible facilities, both local and international experiences indicate that the creation of barrier-free environments are more about appropriate and informed planning and design than they are about costly additions and adaptations. The NCSNET/NCESS report[8] cites the National Environmental Accessibility Programme (NEAP) as indicating that generally the creation of a barrier-free environment does not add more than 0.2% to the overall cost of development if accessibility is integrated into overall planning and design (DOE 1998: 71).

While new buildings and facilities must now meet the requirements of the National Building Regulations of 1986, these regulations are not enforced and many new buildings built on campuses since 1986 remain inaccessible, particularly to wheelchair users. While some attention will need to be paid to addressing the most important physical barriers, such as inaccessible library facilities, the real challenge for institutions lies in integrating accessibility issues into the ongoing development and maintenance of campuses. This is as much an issue of awareness as it is technical design. It is also about flexibility in the manner in which academic services offered by an institution are planned and organised so that barrier-free access becomes a principle in all aspects of academic and financial planning.

Conclusion

As already indicated, addressing the implications of White Paper 6 for higher education cannot be divorced from the very real realities confronting the sector at present. Of particular importance are the Ministry's most recent policy proposals on the reconstruction and transformation of the higher education system and the development of a 'new institutional landscape' (DOE 2002). Although these proposals once again emphasise the imperative stated in the National Plan (DOE 2001b) for institutions to increase access for, among others, students with disabilities, the issue of institutional mergers has been at the forefront of higher education policy debates over the last eighteen months. There is no doubt that such issues have very real implications for the concerns discussed in this paper. It is likely that the implications of the proposed institutional mergers will only become obvious as the restructuring process is operationalised and the process unfolds.

The experiences of students with disabilities in higher education thus far and the nature of the inequalities discussed in this paper suggest that in the process of contestation towards the implementation of the new proposals, the issues confronting students with disabilities will, at best, be given limited attention. The inequalities experienced by learners with disabilities in accessing higher education and in participating equitably in the process of teaching and learning will continue until a real attempt is made to move beyond symbolic policy statements. This involves recognising, particularly at the institutional level, the importance of building the capacity of the system to accommodate the full range of learning needs that exist among the potential and existing student population. Building such capacity must involve a process of systemic change in which the structural and discursive barriers that restrict access and limit participation for all learners are confronted and addressed. Such change offers the opportunity for important equity gains to be made in higher education in South Africa. However, in a climate increasingly defined by 'market' concerns, an historical legacy of inflexibility in the teaching and learning process and the constraints of institutional debt, it is difficult to feel positive about the extent to which such change will be rigorously embraced.

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NOTES

1. White Paper 6 (DOE 2001a) does make some mention of higher education and the implications of the key recommendations of the policy for this band. This is discussed in more depth later.
2. While this paper is concerned with higher education, it draws strongly from work undertaken by a number of sociologists who have contributed to developing the body of knowledge which is now generally regarded as the 'sociology of special education/special needs' and is concerned mainly with exclusion at the schooling level (see especially Fulcher (Aus), Barton (UK), Tomlinson (UK), Oliver (UK), Slee (Aus), Skrtic (USA), Naicker (SA), Booth (UK) Muthukrishna (SA). However there is a growing awareness about the importance of this knowledge in understanding inequalities in higher education. Similarly, the paper and my research are strongly linked to attempts by some academics and most importantly, organisations of people with disabilities in civil society, to challenge dominant understandings of disability and attempt to rather develop a sense of the 'politics of disablement' (Oliver 1990) or at the more popular level, developing a human rights and development model of disability (INDS 1997).
3. With these concerns in mind I have also deliberately moved away from any attempt to define what is meant by learners with disabilities. In this chapter the emphasis is on the barriers experienced by those learners who as a result of a disability may require additional support and/or accommodations to the learning environment in order for them effectively to access the curriculum.
4. The shift away from categorising learners is a principle articulated in White Paper 6 (DOE 2001a). At the schooling level the emphasis is now on identifying the level and kind of support needed by a learner rather than the nature and category of disability.
5. While the more cost intensive support needs of some learners with disabilities is focused on here, as already indicated, the provision of support incorporates two primary elements. Firstly, barriers to learning that already exist should be addressed, and preventing these barriers from occurring in the first place, as well as ensuring that all aspects of the curriculum are flexible and can be fully accessed by all learners. Secondly, a related, focus should be on ensuring that all aspects of institutional life are responsive to these diverse needs. This includes all aspects of strategic planning and organisational development, including: the values and norms that give rise to the culture of the institution; the vision, aims and principles as captured in the institution's policies and practices; organisational and curriculum planning and evaluation; structures and procedures; technical support (including resource management, administrative and financial support); human resources; and leadership, management and governance structures and functions.

6. In White Paper 6 (DOE 2001a) the Ministry commits itself to progressively creating what it calls 'full-service' schools and colleges that will be 'equipped and supported to provide for the full range of learning needs among the learners'. Initially, one primary school from 30 school districts will be targeted and then this sample increased to 500 schools. However, the implementation of these 'first steps' does not preclude the development of greater capacity for diversity being developed at all schools and colleges (DOE 2001a: 23).
7. In both the options discussed the term 'region' could be seen to refer to a cluster of institutions within a particular province or to a geographical region that crosses provincial boundaries. It is likely that the latter notion of region would need to be considered in the organisation of support services.
8. Report of the National Commission on Special Needs in Education and Training (NCSNET) and the National Committee on Education Support Services (NCESS), 1998.

chapter eleven

Changing to New Modes of Knowledge Production on Disability

Chrissie Boughey

Introduction

The South African Constitution, which came into existence as a result of the change in political dispensation in 1994, is recognised as being one of the best in the world with regard to human rights. The significance of the Constitution for disabled people is enormous since it guarantees their rights along with those of every other citizen. The democratic government has not been slow in taking steps to ensure that the rights of the disabled embodied in the Constitution are made evident in practice and not only in theory. The publication of the *White Paper on an Integrated National Disability Strategy (INDS)*, for example, identifies the need for disabled people to be included in, rather than excluded from, what might be termed 'standard' education provision.

While the construct of 'integration' of the disabled into 'standard' schooling has some currency at primary and secondary levels, it has not been examined in any theoretical depth with regard to tertiary education. The purpose of this paper is to explore the construct of access for disabled people in *epistemological* terms. Given that access to higher education is essentially about access to learning rather than access to lecture and seminar venues, what does that access involve when learning requires engagement with various forms of spoken and written texts? The chapter therefore begins by drawing on extant research and theory to construct a framework for understanding access before going on to explore a number of initiatives which have the potential to create new ways of thinking about disability in higher education.

Contrasting models of literacy

This attempt to construct a framework which will facilitate understanding of what the provision of epistemological access for the disabled means begins with theory produced in the field which has become known as *New Literacy Studies* and, more particularly, with the work of Brian Street.

'Traditional' understandings of literacy tend to focus on reading and writing as technical processes involving the decoding and encoding of print. Literacy is therefore understood as cognitive in origin and dependent on characteristics inherent to the individual. People who are unable to decode and encode print in ways sanctioned by 'mainstream' society are then termed 'illiterate'. Street (1984, 1993, 1995) challenges this understanding of literacy, which he terms the 'autonomous' model, by offering an alternative 'ideological' model which perceives reading and writing as practices which arise out of specific social contexts. While the acts of reading and writing do involve decoding and encoding print, the 'ideological' model holds that the construct of literacy is much more than this since it encompasses the values and attitudes people hold in relation to certain kinds of texts which, in turn, influence their willingness to engage with them. Since, according to this model, literacy is dependent on values and attitudes which determine the kinds of texts people engage with as well as the way they relate to those texts, it follows that literacy is a multiple rather than a unitary phenomenon.

Different social groups place value on different kinds of texts choosing to engage with some and 'set aside' others. For some social groups, this might mean that written texts are set aside in favour of spoken texts in some contexts. For others, it might mean that written texts and elevated forms of spoken texts are held in high esteem. The result of this sort of understanding is that the construct of 'literacy' has to be replaced with the notion of multiple 'literacies' some of which are privileged above others.

A 'literacy' then becomes defined as a way of being in the world, a way of being which takes into account the way individuals relate to, and value, different kinds of spoken and inscribed texts.

Acknowledgement that literacy is a multiple rather than a unitary phenomenon makes it possible to identify the construct of 'academic literacy' involving ways of behaving, speaking, reading and writing which are peculiar to the 'academy'. These ways of behaving, speaking, reading and writing result from a set of socially constructed values about what constitutes knowledge and learning. Examination of the construct of academic literacy shows that the ways of behaving, speaking, reading and writing associated with it are essentially 'context reduced' (Cummins 1983) or devoid of support for the construction of meaning. Academic texts in the form of journal articles and chapters in books, for example, are not usually accompanied by illustrations or other devices which will support comprehension. Similarly, the academic lecture, in its traditional form, is just that – a lecture read aloud from a written script or set of notes without recourse to visual aids or spoken interaction. When students in the academy are assessed, the assessment tool is usually the 'essay' or assignment which relies on the ability to produce meanings in writing which, unlike the more informal genres of speech, is devoid of support for the making of meaning.

Context-reduced texts (both spoken and written) are more difficult to access than texts which are 'context-embedded' or supportive of meaning making. Consider, for example, how much more difficult it is to access meaning in an academic journal article, which is 'context-reduced', than in an interactive seminar presentation. The 'ideological'model of literacy allows us to question ways of 'being' associated with the academy because it acknowledges their socially privileged nature. It therefore allows us to question the common sense status of context-reduced texts as the norm in higher education and open the way for the use and production of other types of text which are multi-modal.

In spite of the existence of the ideological model, the autonomous model of literacy which perceives reading, writing, speaking and learning as a set of acultural, asocial 'skills' continues to dominate with the result that a failure on the part of students to demonstrate these ways of being is perceived as 'deficient'. In this case, 'deficiency' can be related to various forms of physical impairment or to social 'disadvantage'. In the autonomous model, the dominant form of literacy becomes the common sense 'norm' and other ways of being, for example in the case of the disabled using sign language or Braille or some other form of assistance to make meaning, is pathologised. Typically, the dominant literacy is also often perceived to bestow cognitive advantages. Claims are often made, for example, that the need to produce a context-reduced academic essay which relies heavily on one particular way to use one form of language leads to the development of superior thought processes even though there is little or no evidence that this is the case (see, for example, Scribner and Cole 1981).

Given the aim of this paper to explore what it means to provide epistemological access to higher education for disabled people, what are the implications of the existence of an alternative, ideological model of literacy? The most significant implication is that the ideological model values 'other' ways of speaking, writing, reading, learning as different but equal to dominant ways. Those ways could involve using sign language, writing using technological devices or having another person transcribe spoken language into print and reading in the sense of being read aloud to. A second implication is that it requires lecturers working in higher education to become teachers in the sense that they stop lecturing and start making meaning in ways which are context-embedded rather than context-reduced. A teaching session which, for example, makes use of overhead transparencies or PowerPoint, makes space for students to discuss questions and problems in pairs or groups and generally facilitates interaction at a number of levels. It allows all students – not just the disabled – to access and make meanings in different ways. Support outside the teaching session in the form of web-based learning materials, hand-outs and course guides also enrich the learning environment to facilitate access. There are also implications for assessment in that the academic essay is no longer privileged and other ways of demonstrating learning are acknowledged.

Potential for new modes of knowing

The ideological model of literacy opens up the way for new modes of knowing and being within higher education. Given the dominance of the autonomous model, however, how can that potential be utilised most effectively? There are currently a number of initiatives in the higher education sector which provide an opportunity for change and it is to these that this paper now turns.

Outcomes based education (OBE)

The establishment of the National Qualifications Framework (NQF) onto which all qualifications must be registered has meant that the higher education sector has had to engage with the construct of the 'learning outcome' since qualifications have to be described in terms of outcomes if they are to be registered on the framework. A learning outcome is a description of something learners will be able to do by the time the qualification is awarded. In OBE, doing is distinguished from knowing, with a concomitant focus on applied or practical knowledge rather than theoretical knowledge. The need to identify learning outcomes for qualifications and the courses/modules which allow learners to achieve those qualifications, has the potential to open the way for the 'other' ways of being valued in an ideological model of literacy. It is no longer enough, for example, to be able to demonstrate theoretical competence by writing an academic essay since the outcomes of a qualification may also require learners to speak, draw, take part in an interview or perform some other demonstration of their learning. The potential for 'multi-modality' is enormous.

In spite of this potential, the move towards outcomes based approaches in higher education has been little more than a paper based exercise in that it has resulted in new curriculum documentation and little or no changes to classroom and assessment practices.

The Higher Education Quality Committee (HEQC)

The establishment of the Higher Education Quality Committee (HEQC), a body responsible for promoting and assuring quality in higher education, represents another opportunity for change, particularly with regard to the way OBE is implemented. Key to the construct of 'quality' in teaching and learning is the notion of 'alignment' in programme design and delivery where the term 'programme' is defined as the set of learning experiences which will allow students to achieve the outcomes specified for the qualification. 'Alignment' involves considering how teaching can facilitate the achievement of outcomes as well as how that achievement should be measured. An 'aligned' programme would thus demonstrate coherence at a number of levels including actual teaching, the availability of supporting materials and assessment. The willingness and ability of the HEQC to use the construct of 'alignment' as an indicator of quality in the audit process is thus crucial in the provision of epistemological access to the disabled. Fortunately there is every indication that this will happen.

The Registration of Assessors

Linked to OBE and the need to assure quality in higher education is the need to train and accredit academics as assessors. Assessment is key to quality since there is little point in registering qualifications on the NQF and establishing standards for those qualifications if the assessment of students studying towards those qualification is not valid and reliable. In this case, the term 'valid' is understood as the ability of an assessment tool or task to measure the outcome it is intended to measure rather than some other outcome. The term 'reliable' refers to the ability of the tool or task to measure performance consistently. The majority of academic staff have little theoretical knowledge of the principles underpinning assessment and tend to assess their students on the basis of their own experience of being assessed. The result of this situation is that much assessment in higher education is questionable.

The South African Qualifications Authority (SAQA) has stated its intention to require anyone assessing performance against qualifications registered on the NQF to be trained and registered as an assessor. Whilst this proposal has been accepted in industry and other circles, it has been resisted in the higher education sector and it is now proposed that institutions should be able to 'blanket register' their own staff as assessors. Should this happen, the potential for change will be limited since it is unlikely that existing assessment practices will be challenged in any significant way.

The Postgraduate Certificate in Higher Education (PGCHE)

It has long been noted as an irony that while it is necessary to have a professional qualification to teach at primary and secondary levels, this is not the case for higher education. As a result, most academics base their teaching on their own experiences of being taught with the result that dominant literacy practices are entrenched without any form of questioning.

The Postgraduate Certificate in Higher Education (PGCHE) is a national qualification (in the sense that it was developed by a Standards Generating Body for Higher Education rather than an individual institution) intended to accredit academic staff as professional educators in the tertiary sector. Developed in unit standard format, the qualification focuses on a number of 'roles' of the educator including the educator as assessor, curriculum designer, learning facilitator and materials developer. Engagement with the learning outcomes developed for the qualification has the potential to prompt academics to question much of what they have been doing as educators as well as what they experienced as teachers.

A number of institutions have now developed, or are in the process of developing, programmes leading to the qualification. The provision of access to academic staff to a programme leading to the PGCHE is likely to be seen as an indicator of institutional quality once the HEQC begins the quality audit process. The availability of programmes will only open the way for new modes of knowing, however, if programme managers/leaders are able and willing to take a critical stance. Whether this will happen is still open to question.

Conclusion

It is evident that, at this point in South Africa's history, the transformation of the higher education system operationalised through initiatives such as the introduction of OBE, the advent of quality assurance and the availability of professional training for educators in the sector has the potential to improve access for the disabled in qualitatively different ways. This will only be achieved however if adequate theoretical frameworks describing the notion of epistemological access are constructed. This paper represents one small attempt to begin building such a framework.

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chapter twelve

Disabled Students, Disability Studies and Disability in Research Practice

Martha M. Laclave

Introduction: Disabled Students

Since Disability Studies and feminist perspectives on disability have emphasised making the personal political, I will start with my own story of disability and education.

I had formal training in music for many years, but, due to progressive hearing loss since the age of 13, I stopped playing music in high school. At age 21 I was examined by a minimum of 21 specialists for chronic ear pain and hearing problems. I often explain some of my story as, 'I stopped counting the number of doctors I have because I didn't want that number to exceed the number of years I have lived'. I have auditory perception disorders, sensoroneural hearing loss. I am hearing impaired.[1]

During such testing and diagnoses for my hearing problems and ear pain (and there has been much hypothesising on both) I was said to have dysgraphia. Some specialists wanted to see a sample of my writing so I brought in a paper I had recently written as a senior anthropology undergraduate. Until that point I had been working with my undergraduate academic advisor on my writing: he tried many approaches and spent many hours with me with the goal of improving my writing. He believed me. This was the first major step; some students or patients never get that far. The specialist at the hospital told me I had to be 're-taught how to write'. During my last semester as an undergraduate I was at the hospital two to three time a week being 're-taught how to write'. I learned how such specialists believed they can approach how I think. Meanwhile, my undergraduate advisor was much more helpful and I still have the guidelines he typed on a half sheet of paper on how to construct a paragraph from *my* perspective. I had to translate my seemingly disjointed thoughts in written form into something understandable and readable for my audience.

I came into graduate school with something resembling a disabled identity. I had written a minimum of 30 drafts for the applications and another undergraduate professor in my department read and commented on every one. I re-evaluated everything I had written as an undergraduate. During the last semester of my undergraduate career I was fitted with my first hearing aid. I had a group of disabled friends. I became active in the community. The truth of the matter is I realised this was a human rights issue.

Once in graduate school, my seminars surrounded issues of resistance, representation, power, and a multitude of ways of describing, critiquing, and finding what is *really* happening. From day one of graduate school in these seminars I struggled to find why disability was excluded from the discourses of race, ethnicity, gender, nationality and other identities. I quickly concluded that disability is 'invisible' to anthropologists, and other social theorists for that matter. Nor is disability recognised as a human rights issue by anthropologists; which is shocking or at the very least disheartening given the humanistic nature of the discipline.

Anthropologists traditionally focus on the issues of oppressed peoples – the poor, peasant societies, immigrant communities, for example. Doesn't disability fit into this? This failure to link the relationships of the disabled community to its larger culture are analogous to a failure to link such relationships as gender and ethnicity to contemporary structures of power. Lennard Davis (1995: xii) has helped elucidate the problem:

> The fact is that disability as a topic is under-theorised – a remarkable fact for this day when smoking, eating a peach, or using a bodily orifice are hyper-theorised. Because of this under-theorisation, which is largely a consequence

> of the heavy control of the subject by medical and psycho-social experts, the general population does not understand the connection between disability and the status quo in the same way many people now understand the connection between race and/or gender and contemporary structures of power. I hope that as a result of the efflorescence of studies on disability from within the community of people with disabilities the day is not far off when the majority will dismiss the current dominant view as 'antiquated' and find it hard to believe that such a regressive understanding of the body could ever have been held by intelligent, progressive people.

I then searched for non-medical literature and alternative histories surrounding disability as well as finding ways of incorporating disability into the social theories spouted in my seminars and everyday speak of social science graduate students. Entering my graduate career after reading important publications such as by Robert Murphy, Irving Kenneth Zola, Jenny Morris and other academics with disabilities has been immeasurably helpful; but until it is realised that many issues need to be addressed and activated by the wider academic community, there is still a long way to go.

Such life experiences led me to my current work in urban Johannesburg. My research concerns surround the age of onset of disability, social movements and community formation. Many of my colleagues question how I function in the field, that my hearing impairments would be difficult for interviewing. They do not ask how my being white or American or female affects the context of interaction in South Africa. My speech has been preserved and I often receive the 'compliment' Irving Kenneth Zola and many people with disabilities receive, which is: 'You know, I never think of you as handicapped'.[2]

I recently became what is known as ABD and a PhD candidate – a big step in the process of earning a PhD. ABD means 'all but dissertation'. This happens after a PhD student passes his or her comprehensive exams and successfully defends a proposal for the dissertation. I was fortunate enough to have a supportive graduate advising committee who understood my learning disabilities. Comments on my seminar papers had been along the lines of 'strong theorising, awkward writing' or 'each sentence you have written should be a paragraph of its own'. I'd like to feel that I have improved upon that. My 'comps' were taken under different accommodation where I could take home and write, closed-book, my exams.

Although I have begun my dissertation fieldwork, it does not mean I am funded by an organisation. Firstly it is difficult to fund qualitative research. Secondly, attracting funders for disability related research is doubly difficult, no matter how cunning one is. This also must change.

Disability Studies through the Lens of Anthropology

Based on my history, my perspective on disability studies is through the lens of anthropology. Although anthropology has a miserable history in South Africa, the discipline has changed. Here I will give a critique of research by disability type from an anthropological perspective and then introduce how the work in Disability Studies has helped changed this. Disability Studies, however, is not without its problems and these too will be highlighted. Perhaps we can even come up with some ideas on how to apply disability to those 'other departments' where disability does not seem readily applicable yet, but is germane to their theories and research practice.

Where there are studies on disability it is often from the medical model of disability where one of the criteria is approaching disability by type -- meaning paraplegic, quadriplegic, cerebral palsied, deaf, blind, etc. What are some problems of studying disability by type? Well, there is upholding the medical model of disability, which I think we all know is counterproductive to a human rights model. The medical model of disability focuses on the individual. The individual is caught in personal tragedy and needs diagnosis and specialised medical treatment. 'Handicap', 'invalid', 'incapacity', 'special', 'dependent', 'challenged', 'abnormal' are all vocabulary infused in medical discourse and is found acceptable in the medical model of disability to the extent that it constructs people with disabilities as objects. More common terms include: freak, gimp, crip or crippled and (a personal favourite) retard. Some of these terms, however, have been reappropriated.

The consequences of using the medical model are that it creates a population that is seen as: dependent on the state; emotional and financial drains on the family; believing that they need to be cured and are curable; believed by authorities to be uneducable and unemployable.

Critiques have been possible through post-modern theories and were applied by disabled activists of the 1970s and 1980s. This, along with recognising disability as a human rights issue, helped form the social model of disability. Theorists agree that the social position of the disabled is culturally created and maintained. Many disabled scholars quickly embraced and actively pursued demonstrating this truth to their realities as an oppressed group on an academic level. This is breaking from a traditional yet still used approach to disability as belonging in a health and welfare framework or medical model of disability.

As a field of study, Disability Studies is a relatively new field incorporating critical theory and the spirit of liberation. It has found a home in Social Sciences and Humanities departments. By placing people with disabilities in wider social contexts, researchers hope to spur on social change. As with the literature on feminism and disability, it is also within disability studies that people with disabilities are not placed within a medical model, targeted as 'ill', or reasons for telethons. Rather, people with disabilities are viewed as social agents. In social science, this means they are not passive actors, but active towards social change.

There is diversity within Disability Studies, feminist perspectives being just one I'd like to highlight. Women with disabilities accuse the feminist movement for excluding them from the mainstream feminist agenda and feel alienated that feminism does not integrate disabled women into its theory, methodology, research, and politics (Morris 1993; Thomas 1999). The issues regarding the disability movement surround male-led direction and women's issues being relegated to the margins as 'special interest' (Begum 1992; Morris 1991, 1993). A feminist theory of disability is needed, according to Wendell, because the oppression of disabled people is linked closely to the cultural oppression of the body (1997).

However, one of my main critiques of Disability Studies, as with most research on disability, concerns the body. Research in Disability Studies is still often focused on disability type. Disability is more than 'body'; it is more along the lines of 'embodiment' and identity. Rarely is disability connected to larger culture and the rights of people with disabilities when only one type of disability is focused on.

I understand disability as a potential site of **identity** creation. Identities are a socioemotional need that are culturally organised.

> Claiming a cultural identity of our own moves us toward reclaiming ourselves from the Other, and establishes us as subjects and active agents of transformation beyond objectified and marginalized Others (Peters 2000: 585).

As conceptually post-modern, 'cultural identity is embedded in relations of power, the politics of difference, community and democracy' (Peters 2000: 588).

From this perspective, the cultural is political, and therefore a terrain of struggle in which resistance is a basis for developing a cultural politics and anti-discriminatory ideology as part of a larger theory of difference and democratic struggle for justice, equality and freedom. In other words, post-modernists redefine culture 'within multiple relations of difference that offer a range of subject positions from which people can struggle against ideologies of the Other and discrimination' (Giroux 1991:233).

The stance of many disability rights activists can be located within this view – particularly with respect to their emphasis on developing a cultural politics (such as Gliedman and Roth's Unexpected Minority), their resistance against societal discrimination and their fight for social justice.

Take this country for example. The history of people with disabilities in South Africa is significant to the further understanding of power, coercion, domination, and hegemony in the workings of apartheid. The creation of disabled bodies aids in the success of achieving control. Mechanisms of disablement are varied: poverty leads to disability; 'accidents' such as road violence; riots and participation in political activity, especially during the 1980s; sports injuries; mining and other labour-related activity are a few examples. All of these mechanisms are political. Disease from lack of medical attention, malnutrition, lack of resources (such as clean water), and the diseases of poverty all contribute to disability. An injury is not an accident, for 'accident' connotes a neutral event without respect to causation, intentionality, and predictability. Sports injuries can be differentially applied according to class. Mining and other industries have killed and disabled thousands of workers. All of these examples have social impacts, creating a controllable population.

Another problem with focusing on disability type is that the richness and diversity of the disability experience is missed. It is also a problem of method. Although Disability Studies and other social sciences, such as history and sociology, has become a bit kinder to the qualitative, ethnographic methods pioneered through anthropology, many researchers do not seem willing to invest the amount of time anthropologists often do in fieldwork. Ethnographic studies on disability have examined disability in several ways. First, they have examined disability qualitatively by cultural immersion; second, they have included international contexts, filling in the void from Disability Studies that tends to focus on North American and European contexts. International settings for disability research are needed because, according to the United Nations, approximately 80 percent of the world's disabled population reside in developing countries. Third, ethnographic studies on disability can focus on tensions within the disabled community, everyday coping, and the various forms of oppression experienced.

As in Disability Studies, a few anthropologists studying disability investigate disability identity. I can think of two ethnographies that consider colliding identities. In Shlomo Deshen's *Blind People: The Private and Public Life of Sightless Israelis,* he identifies and traces the contours of prejudice toward the blind Israelis he worked with and the ways they manoeuvred within and between the blind community and the sighted world. He describes how they position themselves somewhere in the disparate ideas of who they are as blind people: revulsion of the image of the blind beggar, fulfilling a labour ethos by accepting jobs thought appropriate for them (as a switchboard operator or worker in a sheltered workshop) and having guide dogs in a place where dogs are seen as unclean beasts. Other positions concern losing autonomy by seeking the aid of welfare and rehabilitative services, participating in various social circles and programmes available to them yet never being able to establish a long-term love relationship and discovering that blindness was not usually a sufficient base for fellowship. An emphasis on the differences between Ashkenazic and Middle Eastern origins and its role in the blind community dynamics undermined their efforts to organise.

Paul Preston's *Mother Father Deaf: Living Between Sound and Silence* is a good example of disability and its impact on the everyday lives of families. He uses narratives of hearing children of Deaf[3] parents (an experience which is also his own) in the United States to illustrate how they can be 'culturally Deaf'. These cultural meanings of disability are important in that they contextualise the multiple realities of people with disabilities. In doing so, fundamental questions of the social sources of discrimination and disempowerment can be answered.

Again, however, studies by disability type have difficulties answering questions of disability community and its link to power.

Designing cross-disability research poses specific problems. First, many researchers, although trying to include all kinds of disabilities, do so with the omission of those with cognitive and developmental disabilities. Cognitive and developmental disabilities pose ethical dilemmas and methodological challenges in any type of research. Edgerton (1993) and Angrosino (1992) have each invested much of their careers in this greatly unexplored area. They have found new ways of understanding the realities and experiences of people with difficulties in expression and communication. Angrosino has found that the ethnographic interview and narrative are qualitatively different with this population. The anthropologist must not concentrate on what they say but on their abilities to create culturally appropriate metaphors to convey their sense of identity (Angrosino 1992: 172). However, the question of informed consent needs further clarification but the data from these researchers aid in accounting or exploring potential outcomes of the actions of anthropologists.

Another area of concern with *any* disability research is considering what *is* a disability. The response to this is to continually evaluate how disability is culturally constructed. Many dissertations and theses, for example, cull a research sample from hospitals, clinics, physiotherapy groups, rehabilitation facilities, and other disability related organisations. While people with disabilities can certainly be found through such places, what about those who cannot afford such therapy or have gone through their programmes and left? Or, more importantly, where are the voices of disabled people who are well adapted to their lives, and do not frequent medical facilities? Their voices are important to understand how or if a disability community exists.

I've mentioned 'community' a few times already. To me, those everyday tensions that can be found through qualitative research can help identify the spaces that limit finding areas in their lives that are changeable. These are imagined communities, produced by cultural, political, economic, and social structures. In the South African context, however, 'community' was used by the apartheid regime for its own legitimation. South Africans have their own crisis of representation. 'Community' has been used interchangeably with 'race', 'ethnic group', 'nation', or 'peoples' to maintain that 'communities' must also develop 'separately' (Thornton and Ramphele 1988: 30). 'South Africans have multiple identities in common contexts and common identities in multiple contexts' (Thornton 1996: 150). As far as 'the deaf community', 'the blind community', and an assortment of other communities by disability type, redefining community is one way to approach disability across disability types.

Disability community is part of my dissertation research and is compatible with participatory approaches to research. Participatory research is another approach that has gained popularity, but may not be widely used.

Participatory approaches attempt to bridge the gap between theory and practice. They are, however, varied. Some may know this as community-based rehabilitation, emancipatory research, action research, social impact research, participatory rapid appraisal, or research with the goals of empowerment. These approaches are used a lot in development work, and are often difficult to do as a student or researcher. Traditional protocol of writing proposals is challenged with such an approach because funders want 'scientific validity' in proposals – try telling them you'll get it while you are abroad. Other problems such as reporting the cost of reciprocation, that is, how do you compensate for the often personal investments participants make to supply you with data. This is often determined while in the field or during feasibility studies to find what is appropriate.

Nevertheless, the first thing one must remember is that participatory approaches are not a method, but rather more of a philosophy. One cannot just go into the field, ask a few questions, and leave, never to return or have contributed. This mimics the 'detached observer' role. One pressing issue picked up in Disability Studies while trying to make their research more useful and to improve upon the relations of research production is questioning who can do disability work properly? An unequal power relationship already exists between the researcher and researched. The next logical question brought up by scholars Mike Oliver, Emma Stone and Mark Priestly, is whether able-bodied can do disability work properly. These questions are an effort to make researchers more accountable to the people they work with. Researchers are trying to break away from the 'detached observer' role and letting the participants guide and teach. Weren't we taught about the scientific method – where analysing data leads to hypotheses and theories rather than looking for theories in the field?

Participatory researchers also attempt to make research more useful to the population involved. Generally, 'research on disability has had little influence on policy and made no contribution to improving the lives of disabled people' (Oliver 1992: 101). Sure, I'm here to gather data for my research to earn my PhD, but there are also impacts and contributions that I can make while I'm here.

Disability in the Classroom and Beyond Graduation

Despite these problems of research design and its contribution to theorising about disability, disability must be integrated into all curricula. Disability as an issue of *identity* must be integrated into all academic endeavours. I thought a lot about the subtitle to this conference: 'Are graduates disabling?' I interpret this as 'are students graduating from higher education perpetuating an able-bodied ideology?' I think they are. I've made a distinction between the social sciences and humanities, and the 'hard sciences'. For the 'soft sciences', disability is slowly becoming adopted in history, sociology, media studies, literature, and the arts. Disability Studies as a field has contributed to this growth with establishing an organisation (Society for Disability Studies), academic programmes and courses, journals and other publications, and conferences.

But Disability Studies needs to push and expand its discourse into the 'hard sciences', i.e. statistics, biology, engineering, and the like, to integrate disability and lessons of difference into their theories and practice. Disability, when conceptualised as outside 'normal', has played a role in teaching about physiological difference, but it needs to be transferred into humanistic reality, perhaps to find answers to why there is such variation in human biology rather than to the ends of 'fixing' disabled bodies.

One example I can think of where disability can influence a 'hard science' was a paper I wrote during my first year of graduate school. It was required to take biocultural evolution during that first year. I wanted to write a paper that dealt with adult-onset of hereditary deafness through examining reports from geneticists of statistical samples. At that time, I too was focusing only on deafness. For the paper, I found articles from research teams who had taken blood samples for genetic testing from countries around the Mediterranean. They found similar patterns of specific genes but could not explain how they showed up where they did on the ground. These patterns of expression made sense to me. I hypothesised that this form of deafness and the way it was expressed is plausible when considering that approximately 90 per cent of the deaf marry the deaf. Both parents of a deaf child must have the gene for this particular type of deafness to be inherited and the scientists sampled generations of families for their research sample. I would recommend that this research be turned into some sort of reclaiming of history for the deaf in that area.

Research in sciences such as economics, business, and biology can include disability. In Simi Linton's *Claiming Disability*, she makes an observation that lives at the forefront of my mind as I critique any research ever since I first read it. To paraphrase, how can researchers whose studies do not include people with disabilities in their samples claim that their findings are generalisable to the wider population, especially when people with disabilities are the worlds largest minority group? I would like to know how many academic departments in their courses on sampling, research design, or quantitative methods teach their students that when in the field or using pre-existing data that a large chunk of the population may have been missed or excluded in the past? Or would this skew data too much? I'm afraid however, that including a representative sample of people with disabilities in research sampling would challenge some theories in science that they may not be willing to give up.

What I think the reader should take away from this chapter is a better or reaffirmed understanding of research design, that disability is a potential site for identity formation, a sensitivity to making research useful for those who participate and their community, and to think of ways of how to incorporate disability into higher learning so that graduates are not perpetuating able bodied ideology.

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NOTES

1. See Estroff 1993 regarding concepts of chronicity.

2. See Irving Kenneth Zola (1982: 205), especially Chapter 10 entitled 'If Listening is Hard, Telling is Worse'.
3. Capitalising the 'D' in Deaf is to differentiate between being deaf or with significant hearing loss and being culturally Deaf or the cultural experience of deafness. Members of the deaf community and authors are not at all certain of what that means and lack concrete clarifications in their communication and writing. Preston (1994: 13-14) writes: 'For some, difference from others is sufficient to merit cultural designation. Using difference as a criterion, however, bypasses an important component of culture: those aspects which are shared within the group. Many writers have emphasised the distinct language of deaf people. Yet equating language with culture overstates the relationship and ultimately provides a circular definition of Deaf culture, ignoring the variations in sign language fluency and usage within the Deaf community. Other writers have become bogged down in the issue of whether to describe the Deaf as a culture or a subculture'.

chapter thirteen

The Nature of Emancipatory Research on Disability in South Africa

Krish Shunmugam

A Historical Perspective

The history of policy implementation and the passing of legislature pertaining to disability in South Africa can best be illustrated in terms of the pre-1994 dispensation and the post-1994 policy and legislative frameworks. Prior to the 1994 transition to a new dispensation, South Africa adhered largely to the medical model and deficit theory approach to disability, whereby people with disabilities were seen as helpless individuals with deficits, in need of care and help, who could never occupy a fully integrated, equal position in society. Legislation, such as the Bantu Education Act 1953, the Coloured Persons Education Act 1963 and the Indian Education Act 1965, as well as the Vocational Education and Special Schools Act 1937 and the Separate Education Act 1948 fuelled by the doctrines of apartheid, resulted in the organisation of learners according to two segregating criteria: race and disability.

Learners with disabilities were separated from their mainstream counterparts and placed in special schools, which were funded and resourced on the basis of apartheid policies, resulting in poorly resourced schools especially for the vast majority of black learners with disabilities, compared to extremely advantaged schools for a few white learners with disabilities. Hence, black learners with disabilities were unequipped to deal with continuing with higher education. Furthermore, these practices of segregation resulted in the isolation, marginalisation, discrimination and exclusion of people with disabilities in general in all sectors of society. Disabled people were made to feel grateful for whatever assistance was afforded them, and all sense of individuality, choice, rights and freedom were taken from them and placed in the hands of professionals who thought they knew best how to deal with the 'problem' as it was perceived (Fulcher 1989; Peters 1993; National Commission on Special Needs in Education and Training (NCESNET) and National Committee on Education Support Services (NCESS) 1997).

It would be satisfying to say that the policy environment and legislative framework changed in the wake of the 1994 transition to a new political dispensation. However, although the policy and legislative climate has changed, the practical application of the new emancipatory and empowering framework has taken much longer to filter through to the ground level where it is most needed. Disability only received full recognition in South Africa as a human rights issue since 1994, through the Constitution and the Bill of Rights (1996), the Integrated National Disability Strategy (1997), the White Paper 3 on Higher Education (1997), the Education White Paper 4 (1998), the Employment Equity Act 55 of 1998, Promotion of Equality and Prevention of Unfair Discrimination Act of 2000 and the Education White Paper 6 (2001).

Central to these pieces of legislation and frameworks are issues of access, appropriateness and responsiveness of service delivery at institutions such as institutions of higher learning. Together with the scrapping of the medical model in favour of the social rights model to disability, these policies set forth a framework for the equitable distribution of resources and opportunities for people with disabilities in all sectors of society, such as the educational, employment and social sector. They would no longer be perceived as helpless and 'defective', but as individuals with the full potential to become fully integrated, functioning members of society. As espoused within the social rights model, the movement is towards independence, self care, maintenance, integration and normalisation – equality of citizenship for people with disabilities.

Already discussed are the ways in which people with disabilities were suppressed and repressed under the old apartheid regime, and the medical model of disability. However, people with disabilities refused to be consigned to the background as inferior, second-class citizens, and strove for their rights and recognition as equal citizens. The rights of people with disabilities has not been gained without struggles, and has been attained largely through the efforts of disabled people themselves, learners, educators, parents, policy makers and advocates who organised around political action and pressure groups such as the South African Blind Workers Organisation (SABWO) and Disabled People South Africa (DPSA), amongst others.

Nonetheless, legislation does not necessarily guarantee implementation, and at present, the key issues being faced by people with disabilities is the practical application of these empowering principles within a context that can benefit them. Currently, people with disabilities continue to face barriers to their full inclusion and integration into society, particularly in the arena of education and employment, which could account for their poor representation in these fields. Aside from having to deal with the physiological and physical consequences of their impairment, people with disabilities still have to contend with societal norms, attitudes, behaviour and even now, policies, that are discriminatory towards them.

The concept of research and its application in the field of disability

> Research is a tool for seeking answers to questions, focusing either on the advancement of general knowledge and gaining a fundamental understanding of social reality, or seeking solutions to specific problems and addressing practical issues (Sarantakos 1993; Neumann 1997).

At present, as little is known about disability outside the medical model perspective, there is a need for exploring, enumerating, describing and understanding the key concepts. Previously, research and administration into disability was the province or primary domain of professionals, who had little or no personal experience of the issues impacting people with disabilities. This has resulted in information from a skewed perspective, often coloured by the themes of the medical model, and researchers' perceptions of the subject matter.

In the current climate, though policies and legislation on disability have been formulated and put in place, without their concomitant practical application, there is a growing need for research on disability. Research involving the active collaboration, participation and cooperation of researchers, practitioners, lay people, organisations and communities, with a view to addressing the problems, barriers and issues currently experienced by people with disabilities, is the most practical solution to this disparity.

In this regard, the White Paper on an Integrated National Disability Strategy (Office of the Deputy President, 1997), recommends that:

> The Office on the Status of Disabled Persons, Office of the Deputy President, in consultation with the Human Sciences Research Council (HSRC), South African Human Rights Commission (SAHRC), the South African Disability Institute and other research agencies, universities and the South African Federal Council on Disability (SAFCD), facilitate the development of national guidelines and minimum standards for inclusive research on social, economic and participation issues that affect the lives of people with disabilities and their families.

Furthermore, according to the White Paper on an Integrated National Disability Strategy (1997), people with disabilities are best equipped to changing perceptions and attitudes towards disability, and should therefore play a central role in the development of strategies and projects through their legitimate organisations. This proposal of a more central role for people with disabilities heralds a shift in power away from professionals, towards people with disabilities. At this juncture, however, very little research into disability has actually been conducted by people who are disabled. Specifically, research is needed in various sectors of disability, namely, the educational system, the employment sector, sports and recreation, and the dynamics of relationships between disabled people, their peers, families and society.

Being the coordinator of the Disability Unit at the University of Natal, I was afforded the opportunity to conduct research into the current barriers experienced by disabled students. Some of the key themes that arose from the research, as well as recommendations and suggestions from both students and government for dealing with these barriers are addressed below.

Barriers experienced by disabled students at institutes of higher learning

Although the research conducted by the Coordinator of the Disability Unit focused on visually impaired and blind students studying at the University of Natal, the outcomes that emerged from the study should not be restricted to this narrow point of view. Indeed, it was found that the emergent themes could be extrapolated beyond the research's physical paradigms to include other education facilities, and most, if not all, students with disabilities.

Access of students with disabilities on campus

One of the most significant themes that developed from the study, which students expressed as a barrier in their studies, was the issue of access. This included concerns about physical access, as well as timeously obtaining text, study and course material in accessible formats. With reference to physical access on campus, students raised concerns about the lack of proper and accessible signage, markings on stairs and elevators, the obstacles that were in their paths, as well as their general orientation and mobility around a large campus, its various buildings and residences.

The issue of adequate physical access was also raised in the White Paper on an Integrated National Disability Strategy (Office of the Deputy President, 1997), where it was put forward that educational institutions should take steps to improve and ensure the physical access of all students with disabilities. In this regard, most universities, including the University of KwaZulu-Natal, have indicated, within their policy frameworks, that the physical environment of the campus would be improved and structured such that access for students (and staff) with disabilities would be facilitated. In addition, the students suggested networking the disability unit with specialist non-governmental agencies in planning and coordinating a full orientation programme for disabled students, implemented in advance of the start of the academic year. This has already been put in place, and also utilises the services of returning students with disabilities, to facilitate the acclimatisation of first year students with disabilities to the campus.

The Education White Paper 6 (2001) makes reference to the duties of institutions of higher education, in terms of providing a flexible curriculum and assessment policy which is accessible to all learners. However, in reality, students with disabilities, in the case of this research study, experienced problems and delays in obtaining their course and study material, and library texts in an accessible format. This does not provide an academic environment for the student with disabilities conducive to performing according to their potential. This limitation results in the misconception that students with disabilities, particularly visually impaired students, are under-achievers, or perform poorly. It also becomes a frustrating experience for students to convert large quantities of study material into an accessible format. Often this problem or task is left to the student to resolve.

The students further raised the point that they had to adapt to new modes of study and technology and that during tests and exams, they were obliged to adhere to the institution's format of assessment, such as using computers, rather than the methods that they were more comfortable with, such as Braille. Recommendations made by these students, to surmount this barrier, included developing a library for visually impaired students, with copies of texts in electronic, Braille and/or audio format. The university disability unit also undertakes the training of students with visual impairments, in the use of computers with specialised software, to acquaint them with the adaptive support technology available to them. Closely linked to the issue of access, was the recommendation by students that a permanent support structure be set up under the auspices of the disability unit, to ensure a more committed, efficient and dedicated access service.

Provision of resources (specialised technology and assistive devices)

The research revealed that central to accessibility to education for visually impaired students, is the provision of specialised technology and assistive devices which facilitate the provision of accessible study material modelled on students' needs. Current technology enables students with visual impairments to obtain study material in Braille, in zoom text (text in a magnified form), text in audio format or in other electronic formats. The subjects reported that the provision of technological resources is a milestone development in their education at tertiary institutions. Evaluation of students' academic results illustrated that there had been a significant improvement in their results subsequent to the university's provision of specialised technology.

Although students with disabilities are still experiencing barriers to education the provision of specialised resources has enabled them to compete on a more equitable level in education. Students had complimented the university in addressing the technological needs of the students with visual impairments. Vital to the provision of these resources is the students' ability to use these specialised technologies effectively. Some of the resources such as computers with speech synthesiser software ('Jaws' TM), will require the students with visual impairment to receive training to use this facility. It is important that they receive the necessary training to use these specialised technologies. Also these resources must be strategically located to allow for easy access and a comfortable means of study.

Medical and psychological needs of students

Due to the strong emphasis that is placed on one's disability, society tends to ignore the personal psycho-social and medical needs of people with disabilities. Although some of these needs may appear to be incidental or insignificant to the mainstream students, they are of vital concern and are highly significant to students with disabilities. Quick access to medical treatment or help, access to ablutions, laundry, the kitchen or other related resources on the campus, is a major concern to students with disabilities. These needs may appear secondary to education, however, it influences the decisions of students with disabilities and their families in terms of their admission to university and residences. The students with visual impairments requested that some of their basic needs especially at residences should be addressed. These requests were not additional demands on the university, but rather a request that the services at residences are accessible and user-friendly for students with visual disabilities.

Communication, liaison and networking with the disability unit

The lack of communication, close liaison and networking between the faculties, schools, programmes and the disability unit was a serious limitation as it resulted in the lack of understanding of the needs of students with disabilities among the lecturers in the various faculties. Their lack of awareness also resulted in their ignorance of the specialised services that are available for students with disabilities. Another consequence was that there were inconsistencies amongst the various faculties, schools and programmes on the degree and nature of support services provided for students with disabilities. In cases where there was close cooperation between lecturers and the disability unit or between lecturers and the students, reasonable accommodations were achieved in relation to the special needs of the students. Students recommended the development of a closer working relationship amongst the parties involved, in the interests of fostering a consistent, barrier-free environment that promotes understanding and accommodates the special needs of students with disabilities.

Attitudes and Perceptions

On a 'social' level, another debilitating barrier indicated by students with disabilities are the societal norms, attitudes and behavioural responses, not only of their peers, but also by the academic and support staff on campus. In the study, all the interviewed students agreed that there is a lack of understanding amongst staff and students, as to their special needs. Students reported that the negative attitudes and perceptions of staff and lecturers were one of the strongest barriers and limitations to their education. It influenced the type of academic support they received and their ability to perform. The prevailing attitude, a legacy of the medical model and deficit theory, is that these students with disabilities need help, and are incapable of fending for themselves, or of studying at the same level as their counterparts. According to the students, although some peers and staff are helpful and accommodating, there is a large percentage that does not accommodate the special needs of students and have unrealistic expectations.

One student reported that lectures were ineffectual to students with visual impairment because the lecturer continuously made reference to teaching aids which could not be seen by this student. These sorts of barriers, arising from the ignorance of lecturers about the special needs of impaired students can be overcome with the assistance of the disability unit, by educating lecturers on understanding the potential and capabilities of students with disabilities, how to effectively address their needs, and provide information in an accessible format. Lecturers who maintained close liaison with the disability unit and took time to get to know the students with disabilities better understood the students and made reasonable accommodations. Students felt more confident about their capabilities and produced good results.

It was also reported that there are strong stereotypes, attitudes and perceptions amongst the student population. Subjects reported that the students thought that they were on a pilot study or at the university for experimental purposes, and students could not believe that they were studying the same course or writing the same exams.

Some of the visually impaired students that were interviewed voiced the opinion that the system of separate education resulted in students being reluctant or even afraid to associate or engage with students with disabilities.

The barrier of attitudes and societal perceptions is not insurmountable, and students were optimistic about a change in the current negative stereotypes and philosophies. They suggested dispelling the misconceptions about disability by increasing awareness of disability issues, on and around educational institutions, by holding informative workshops, campus-wide campaigns, and developing explanatory and educational handbooks, pamphlets and posters, which would provide accurate and informative facts about disability, the needs of students with disability, available support services and improvements to existing programmes and policies, and the potential and capabilities of students with disabilities.

In a similar vein, the Education White Paper 6 (2001) advocates the formation of support teams at national, regional, local and institutional level, which would evaluate programmes, diagnose their effectiveness, and suggest modifications. In addition, the Department of Education proposes the launch of an information and advocacy campaign, to communicate policy proposals, rights, responsibilities and obligations, with reference to disability, as contained within the White Paper. Furthermore, the department intends to mobilise community support of these issues. The White Paper on an Integrated National Disability Strategy (1997) proposed stimulating public awareness and understanding of disability issues by the development of multi-sectoral awareness strategies, awareness projects and programmes aimed at government and the media, and increasing the visibility of people with disabilities in the media. The education of people in the public sector on disability and the implications of the social model would also be promulgated.

Melding these various issues, and addressing them, the White Paper on an Integrated National Disability Strategy (Office of the Deputy President, 1997), states:

> It is recommended that the Department of Education, in consultation with the councils of technikon and university principals, the South African Federal Council on Disability (SAFCD) and other stakeholders, facilitate a process to develop inclusive strategies that will:
>
> (a) remove all discriminatory practices and barriers in admission policies, examination procedures, decision-making processes, etc;
>
> (b) place at the centre of the transformation debate the need to create an inclusive environment that caters for the diverse needs of all students. This should be done through the development of national norms and

minimum standards for barrier-free design, access to communication support, appropriate technology, etc. and

(c) facilitate representation by students with disabilities as a distinct constituency on all forums and governance structures.

Students with disabilities or special needs who attended special schools or separate education seem to experience problems with adjustments and integration into the university. They tend to display low self-esteem, lack of confidence or assertiveness and lack the necessary self-independence skills. It appears to be a traumatic transition. Students with disabilities develop the image that they have deficits and are inadequate, due to the stereotypical attitudes and perceptions of disability and separate education reinforced by the functionalist theory.

Need for research in the disability movement

Participatory Research

Participatory research supports a developmental, emancipatory approach to research in the field of disability. This type of research requires the active involvement or participation of the researcher, participants, members or organisations. They are actively involved in the research from the period of formulating a topic to the implementation of the findings (Sarantakos 1993).

People with disabilities engaging in participatory research bring personal insights, individual experiences and knowledge which are of central concerns to them. Hence participatory research will bring dedication and commitment to the development of knowledge in the field of disability, which has been historically neglected.

Emancipatory research – Advocacy of needs

Professionals who had no personal experience in the field of disability have historically dominated all areas of disability, namely, employment, education and society in general. This is one of the major reasons disability has not developed and does not receive full recognition (Peters 1993; National Commission on Special Needs in Education and Training (NCESNET) and National Committee on Education Support Services (NCESS) 1997). This has disadvantaged people with disability. Emancipatory research will put power and authority back in the hands of people with disabilities. This will enable them to take their rightful place in society and be recognised as full citizens. People with disabilities participating in research on disability will contribute to them becoming experts in their own field of interest. They will portray an empathetic insight and approach to disability. Hence, there will be continual growth and development in the field of disability (Office of the Deputy President 1997).

Theory testing

South Africa has adopted the social rights model to disability, which fosters a developmental approach to disability. This thereby ensures the full integration of people with disabilities in society. It pursues an inclusive approach. Research will provide the necessary information on whether institutions are realistically applying the theoretical framework of the social rights model to disability. The findings from the research study at the University of Natal revealed that in policy the university has adopted the social rights model, which is reflected in the their disability policy (NCESNET and NCESS 1997).

Emancipatory research which allows for theory testing and theory building, empowers people to challenge historical, attitudinal and perceptional barriers that held back the development of disability.

Provides credibility and respect to research findings and facilitates implementation

Knowing that the information and knowledge on a particular subject, in this case, disability, has been developed through research, affords it due respect and credibility. The institution, organisation or structures become aware that the information is socially scientific and generated through participatory research whereby key role-players were actually involved throughout the process of the research. Therefore the findings are legitimate and authentic, and demands credibility and respect. These types of research facilitate implementation of procedures and policies that have developed from the findings.

Explore and evaluate social realities

In emancipatory research, people with disabilities will be empowered to explore and evaluate the current social realities of people with disabilities in the various sectors of society. It is through exploration and evaluation of contextual situations that further questions emerge in relation to disability and development. Considering that disability is still in its initial stages of development and that there are still negatives attitudes and perceptions of disability that are being perpetuated, it is vital that all avenues of disability are explored for consequential limitations, and continuous evaluation needs to take place to facilitate development. Effective exploration and evaluation can only be based on factual information that is developed from research. Emancipatory research will provide first-hand information from people with disabilities on the development of the disability field.

Basis for future research

Research that is conducted to explore the status of disability will provide a descriptive account of the current situation of disability. These research findings form the basis for future research, and allow for more in-depth qualitative research in more specific directed areas of disability, for example, availability of technical resources and support services in educational institutions for learners with disabilities, the attitudes of educators to learners with disabilities, etc.

The way forward

Disability as a human rights issue in South Africa is given full recognition in the Constitution and the Bill of Rights (1996) and other policies on disability. People with disabilities should enjoy equal rights as full citizens. However, the legacies of the past have resulted in consequential limitations in the various fields of disability, and these need to be appropriately challenged. Hence, development must take place in all the sectors of disability. People with disabilities must be encouraged to take their rightful place in society and to advocate for their needs. However, this requires research and development.

Research must be encouraged amongst persons with special needs in higher education and in the various sectors of disability. Appropriate incentives and strategies must be put in place to facilitate research, for example, provision of funding for research by people with disabilities on disability, post-graduate qualifications, honours, masters or doctorate degrees awarded for research work carried out in the field of disability. Programmes or courses or even diplomas and degrees on disability studies can be introduced. These programmes should also be introduced to students at secondary schools who show interest in the field of disability.

Disability must be strongly featured in diversity programmes at institutions and organisations. Institutions of higher learning must increase their enrolment of students with disabilities and there must be reasonable accommodation of their special needs for these studies. In light of the new dispensation and current policies on disability, tertiary institutions are developing policies on disability and adopting an integrated inclusive approach. They have also begun to enrol students with disabilities. Some institutions have established disability units or disability programmes to provide support services to students with disabilities.

The establishment of disability units has resulted in the universities directing all their services for students with disabilities to the disability unit. Universities have become dependent on the disability unit to provide all support services to students with disabilities. If students with disabilities are not fully integrated in all sectors of the university, then they are still victims of the discriminative practises of the past.

Research and study, the implementation of disability awareness programmes, as well as the active cooperation of all relevant role-players, are all keys required to determine the extent to which students with disabilities are integrated into university, and people with disabilities into society, as well as the barriers to this goal that remain.

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chapter fourteen

Disability Studies: Its role in transformation and development

Robert Masambo

In this chapter I wish to share some thoughts on the importance of Disability Studies programmes and how these studies can contribute to the agenda for transformation and development.

As we debate this topic, it is imperative to contextualise where the disability rights movement comes from, and its objectives and gains achieved over the past two decades, particularly within a South African context. It is also of utmost importance to assess the role played by ordinary members of society, in particular those without disability, and especially the role played by academic institutions in building a society that promotes and protects the rights of all its citizens in a caring and empowering manner.

However, I would like to concentrate on the role played by ordinary members of civil society, in particular those without disability.

All of us can be witnesses – and in particular those who have been actively involved in the disability rights struggle over the past two decades – that the majority of professionals, academics, church leaders, workers and community leaders participated in a very limited manner in the struggle for the emancipation of persons with disabilities. The involvement of the majority of people from these sectors was based on ignorance and the willingness to help without finding out from people with disabilities themselves as to how best assistance could be extended. One has however to acknowledge that there were a few individuals who managed to grasp the crux of the disability rights struggle, i.e. that it is disabled people themselves who should liberate people with disabilities, by being in control of their own lives and issues affecting them.

When people with disabilities talk about gaining their looted rights back, you find academics, professionals, church leaders, community leaders and many others wondering as if they have never heard about rights ... as if they have never heard of equality ... as if it is all new and a dream for people with disabilities to lead a normal life as opposed to being statistics and charity cases.

All these scenarios and experiences resulted in distrust between service providers and persons with disabilities.

Therefore, the subject under discussion today, intends to bring harmony and create a conducive platform, a platform from which a new cadre will emerge. This cadre will be constituted by an equal partnership between persons with disabilities and the so-called non-disabled. These processes should firstly be based on the broad knowledge, experience and history of the disability rights movement. This implies that all contributions made by the disability sector should be recognised and become the basis for any Disability Studies programme. Failure to do so will result in entrenching further divisions and disputes and which might not result in a relevant strategy of building the necessary knowledge base.

Secondly, a Disability Studies programme should at all times focus on bringing on board people with disabilities and parents of children with disabilities. Some academics may want to argue and present excuses in order to divert and prevent people with disabilities from benefiting by using words such as 'people with disabilities and parents of children with disabilities will lower the standards as they are not academics'. We should however acknowledge that these are primarily words used by the anti-progressive forces.

We all have to realise that people with disabilities do not have access to massive resources, in particular finances, and therefore we all have to work together in order to raise sufficient financial resources to facilitate equal and meaningful participation by disabled activists. Without this support the programme will truly be meaningless to persons with disabilities.

All the said processes will enable the country to build a cadre which understands disability and its politics.

The processes will result in having a broader cadre participating in the disability struggle because surely the struggle is not over but has just begun. We have to date but merely succeeded in placing the issue of disability rights on the development and reconstruction agenda. We now have to accelerate action to ensure that the enabling policy framework and awareness created during the first decade of liberation in South Africa, is translated into visible change in the quality of lives of people with disabilities by removing barriers that hinder our full participation.

One of the biggest barriers remains a lack of in-depth understanding of the concept of disability among academics, and consequently the professionals that pass through institutions of higher education. The implementation of our enabling legislative framework is therefore often extremely problematic and retrogressive, as strategies fall back on old and outdated concepts of 'deciding for' and 'doing for', 'segregation and isolation' – 'building supporting industries around individuals rather than addressing systemic barriers', etc.

Introducing a Disability Studies programme at the University of Cape Town therefore becomes a signal of hope not only that we will gradually transform UCT to accommodate in **all** its faculties students with disabilities without any reservations, but also that the university will equip students across faculties with competencies that will enable them to contribute in a more empowering and holistic manner to inclusive development and reconstruction. This programme will hopefully also become a catalyst for transformation and change within other universities.

The programme should assist in consolidating South Africa's experiences with regard to disability issues and therefore enable us to participate, not merely as participants, but as leaders in the global village when it comes to disability matters.

We are in an advantaged position to have such a programme unfolding in South Africa and therefore one question we need to ask ourselves is how we see ourselves making meaningful contribution on the African continent within the context of the New Partnership for Africa's Development (NEPAD) as well as the Africa Decade on Disability. This should include visions on how we can strengthen structures such as the Southern African Federation of the Disabled (SAFOD), Pan African Federation of the Disabled (PAFOD) and others in ensuring that we establish ourselves in order to have intellectual authority on disability matters in Africa.

It is important to understand the context of 'intellectual authority' on disability matters in Africa. In my opinion intellectual authority on disability matters in Africa will not imply that we become a big brother to all African states but rather that within the context of *ubuntu*, we work together without any prejudice with our brothers and sisters on the continent. Furthermore, it also means that people with disabilities also claim ownership, instead of reserving this right for a few fortunate professionals or individuals.

Taken as a whole, this transformation and development process will foster the growth and rejuvenation of Disability Studies programmes globally as it will consolidate all experiences of our country, empower people with disabilities, their families, academics and professionals and transform them into engines of revolution.

It is important to remember at this gathering that we are opening a new window into the history of disability of which our fallen heroes and heroines such as, among others, Friday Mavuso, Maria Ranto, Harry Mohale, Pindy Mavuso and the many will be proud of. Our fallen heroes and heroines will be proud to see an emergence of patriotism, comradeship and friendship amongst people with disabilities and the academic world, because this is all they've been advocating for during their lifetime.

Section 4

The Way Ahead

Sandy Lazarus

Shuaib Chalklen

Statement of Intent: Conference participants

chapter fifteen

The Nature of Emancipatory Research on Disability in South Africa

Sandy Lazarus

What is emancipatory research?

Is emancipatory research relevant and appropriate?

Practical challenges in conducting emancipatory research

In conclusion

Research

- The 'noun' = A particular activity
- Investigation/exploration – to answer questions
- Aims:
    - to build knowledge
    - to develop theories
    - to solve problems
- Process / Product
    - Diverse approaches and methodologies
    - Quantitative/qualitative approaches

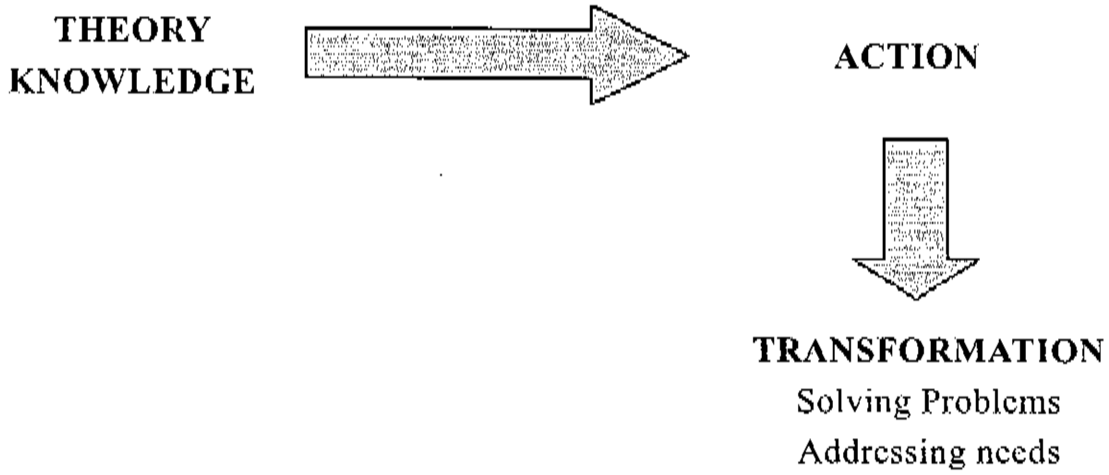
‘Emancipatory’ Research

- The ‘adjective’ – the ‘how’!
- Different terms:
    - action
    - participatory research
    - intervention research
    - community research
    - ‘emancipatory’ research
    - (reflecting a metatheoretical view)
- Key characteristics …
- The ‘why’ and ‘how’ of the research activity is important.

Key Characteristics

> Action research aims to contribute both to the practical concerns of people in an immediate problematic situation, and to the goals of social science, by joint collaboration, within a mutually acceptable ethical framework (Rapoport 1970).

- An activity that has social usefulness and contributes to building knowledge and theory



THEORY
KNOWLEDGE

ACTION

TRANSFORMATION
Solving Problems
Addressing needs

- Theoretical framework = **critical social theories that challenge power relations**
- Process and Product are important

  ⇩

  (The' how' is important!)

  Researcher – Researched Relationship:
    - Power
    - Partnership
    - Participation

Diverse, appropriate research methodologies used

Practical Challenges

- This is NOT a 'soft' option!
- Rigorous research activity
- 'Empowerment' challenges:
    - 'letting go' of hierarchical academic relations
    - sharing skills and knowledge
    - participation realities
    - accessibility
- Product challenge.
  Connecting with action
- Time and money challenges.

References

Rapoport, RN 'Three Dilemmas in Action Research' in *Human Relations* 23:4. 1970: 499-513.

chapter sixteen

Monitoring the INDS[1] in relation to graduate studies

Shuaib Chalklen

Key achievements

- Need for a paradigm shift from medical to social model.
- Areas that will require change.
- Vision: A society for all.
- Important labour and other legislation and policy.

Key challenges

- One of the important challenges confronting the disability movement in terms of higher education is not only the need for access but more critically, outcomes.
- Under what conditions does discrimination change?
- Does the rights-based approach lead to greater access and under which conditions?

Monitoring

- This is not a difficult process, but what is done with the information? What is the role of the disability sector?

- Assume we have actual cases of education exclusion or overt discrimination e.g. do we know what a full service university costs? Challenge for allies in institutions to gather information, assist with holding institutions to account.
- How do we develop a voice for disabled academics and students?
- Do they understand our model/agenda?

NOTES

1. Integrated National Disability Strategy White Paper, 1997.

Statement of Intent on Human Rights, Disability and Higher Education

Adopted at the conference held at UCT Middle Campus, Cape Town from 25 to 26 January 2003.

We the participants of this conference

Noting that:

- This conference is constituted of representatives from the Disability Sector, including organisations of disabled people as well as organisations providing services to people with disabilities, Institutions of Higher Education, Government Departments and Provincial and National offices on the Status of Disabled Persons (OSDPs).
- The rights of children, youth and adults with disabilities are entrenched in the South African Constitution, enabling legislation and the Integrated National Disability Strategy (1997). The right to equitable and non-discriminatory educational provision is further articulated in policy governing the education sector. White Paper 6 and the National Plan for Higher Education provide a framework for the implementation of these rights within higher education institutions.
- While inequalities in the schooling system remain the biggest barrier to access for people with disabilities to higher education, barriers within the higher education system further undermine their equitable participation within higher education institutions. These barriers serve to: restrict access to higher education programmes for students with disabilities; create unsafe and alienating physical and psychosocial learning environments; and undermine their capacity to participate equitably in the process of teaching and learning, thus limiting their opportunities to succeed.

- These inequalities will continue until institutions fully embrace a commitment to meeting the full range of diverse learning needs that exist among the student population in South Africa, including those of students with disabilities.
- The higher education system is also by and large failing to produce graduates across all disciplines that are able to responsibly and effectively contribute to the creation of equal opportunities for people with disabilities in all facets of our society. The challenge remains for the development of graduates who are able to contribute to the creation of a fully inclusive society. The commitment to meet this challenge involves ensuring that the core functions of higher education, namely teaching, research and service delivery are relevant and responsive to the diversity of South African society.
- This includes ensuring that disability related issues, within the framework of a human rights and development approach to disability, are integrated into the content of curricula across all disciplines. It further involves the use of research methodology and the implementation of service delivery initiatives that create opportunities for the active involvement and equitable participation of disabled people and their organisations.
- Despite the important requirements specified in the Employment Equity Act (1998), many higher education institutions have failed to make any meaningful inroads towards the employment of people with disabilities in both their academic and support staff complements.

Reaffirm that:

- Self-representation by persons with disabilities and the formation of partnerships with structures of people with disabilities is central to the building of an inclusive education system. This includes the valuable partnership between institutions of higher learning and Disabled People's Organisations, including international organisations, as well as between members of the academic community and people with disabilities.

Therefore we:

- Call on the government and all institutions of higher learning to acknowledge their responsibility towards the creation of equity for people and students with disabilities.
    - This includes the development of effective plans of action that will operationalise the key imperatives of White Paper 6 within the framework of the priorities outlined in the National Plan.
    - It further includes embracing the notion of diversity and addressing the learning needs of students with disabilities within all key transformation processes taking place within institutions. Of particular importance are those to address the quality and relevance of teaching and learning as well as the provision of effective teaching and learning support mechanisms within higher education.
    - It also includes taking seriously the employment of people with disabilities and the provision of reasonable accommodation to enable them to participate equitably within the work environment and have the opportunity to contribute meaningfully to the institution.
- Call on the government to ensure that adequate and sustainable funding mechanisms are put in place within the overall framework for funding public higher education to ensure that institutions are financially supported to meet their obligations to students with disabilities and contribute to the creation of a more equitable society.

While the primary responsibility for addressing these challenges rests with the government and the individual institutions, we as the participants at this conference commit ourselves to actively engage with these processes within our own institutions and organisations to meaningfully contribute to the change process.

Furthermore:

- We commit ourselves to supporting the development of disability studies programmes that embrace and build knowledge around a human rights and development approach to disability, particularly within the African context, such as the Disability Studies Masters Programme at the University of Cape Town. We will also continue to lobby for the emergence of similar programmes at other institutions of higher learning.